INDEPENDENCE AND CONTROL:

TODAY'S DREAM, TOMORROW'S REALITY

REVIEW OF SUPPORT SERVICE NEEDS OF ADULTS WITH PHYSICAL DISABILITIES

Review Completed by:

Centre for Research & Education
in Human Services

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This Review was conducted for the Ontario Ministry of Community and Social Services by the Centre for Research & Education in Human Services in conjunction with an Advisory Committee representing consumers, voluntary associations, and service providers.

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FOREWORD FROM THE ADVISORY COMMITTEE

This Review of Support Service Needs of Adults with Physical Disabilities in Ontario is a comprehensive study based on a thorough research process carried out by the Centre for Research & Education in Human Services. As an advisory group of individuals, we have worked closely with the Centre at each stage of the Review and have found the entire process to be a positive and constructive experience.

We are pleased to endorse the report and the recommendations of this Review.

We believe this Review should now become the impetus for improving support services for physically disabled citizens in Ontario. There is much in this document to enable community agencies to provide better quality support services; there is much here to enable the Ministry of Community and Social Services to develop strategies and alternatives for supporting more people with physical disabilities in our communities; and there is much here for individuals with disabilties, their families, and consumer organizations about how individuals themselves can gain more independence and control.

We look forward to prompt action on this Review, in order that the dreams people hold today can become reality in the very near future.

Review Advisory Committee June, 1988.

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PREFACE

There has been enormous interest throughout Ontario in this Review of Support Service Needs for Adults with Physical Disabilities. This has been reflected by attendance at community meetings, and by the number of letters, phone calls, and reports that have been forwarded to the research team.

We have received tremendous cooperation during this entire Review. Consumers have willingly shared their stories, concerns, and dreams. Service providers helped the research team access key players in their communities, and shared a great deal of information with us.

We especially want to extend our thanks to members of the Review Advisory Committee who were most helpful during the entire process and to members of the Ministry Steering Committee who provided support and information whenever they were called upon.

This Review has utilized a blend of qualitative and quantitative methodologies in conjunction with a policy analysis perspective. The research process represents a comprehensive and valid approach to service development and change. The recommendations address issues in several areas, including policy, program implementation, and strategies for change. This Review augers well for the next stage of policy development and implementation.

The Research Team

John Lord
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SUMMARY

This comprehensive Review has several overall objectives:

- to determine the nature of the support services needed by physically disabled adults to assist them to live in the community.
- to review the Support Service Living Unit Program and the Attendant Care Outreach Program.
- to assess the experience in other jurisdictions with various models of independent living assistance.
- to develop policy and program options for personal support services for physically disabled adults.

The Government's paper, Challenges and Opportunities (1986), describes a Multi-Year Plan related to deinstitutionalization and community living for people with developmental handicaps. This Review is the first step in developing a comparable thrust in the physical disabilities area.

The Review has utilized a research design involving surveys (176 disabled consumers and 174 attendants), in-depth interviews with individuals and small groups (a total of 175 consumer leaders, consumers of SSLU and Outreach, service providers, key informants, Order-in-Council recipients, etc.), community meetings, site observations, literature review and policy analysis.

Major Findings

1. Needs

- Certain core needs are often unmet for individuals with physical disabilities. These needs include financial security, health and nutrition, safety and comfort, and personal growth and relationships.

- Independence and control are the predominant needs for people with physical disabilities. Consumer perceptions validate this finding:

  - fear of institutionalization
  - desire for consumer representation and participation
  - independence increases for consumers with support services.

- There is wide variation among consumers vis a vis areas in which they wish to have more control.

2. Impact of SSLU and Outreach

- Support programs have contributed enormously to personal development and independence.

- Families have experienced relief from burden of ongoing caregiving and from financial worries.

- Positive changes in the lives of consumers have increased life expectations for disabled individuals.

3. Supports and Services Limited

- Attendant care is underfunded: the real need for attendant care is estimated to be 3-10 times higher than the current level of service.

- The needs of the estimated 1,000 people with physical disabilities in chronic care institutions have generally been ignored.

- Uneven service development has resulted in regional disparities, particularly with the Outreach program.

4. Analysis of Models of Support Service

- Housing is inextricably linked to the method of support service delivery, expecially in the older models of support service.

- The goals of independent living and community integration are not always successfully achieved by the different support service models.

- The organizational structure of a particular model of service delivery is dependent upon the philosophical orientation of the sponsoring group and its leadership.

5. Restrictive Policies of Support Service Programs

- Barriers to gaining access to services include limited amounts of funding for programs and narrow eligibility criteria. Policies related to severity of the disability, number of hours of support required, ability to direct one's own care, age and marital status, and nature of disability all combine to eliminate many people who require service.

- Once receiving services, consumers encounter policies which prevent their needs being adequately met; examples include the role of attendants being defined too narrowly, hours that are limited and inflexible, etc.

6. Multiplicity of Agencies

- Most people receive their support from 2-3 agencies; consumers express frustration with having several attendants from agencies with different regulations.

- Lack of co-ordination among agencies providing service to an individual causes fragmentation and duplication.

- There is consumer dissatisfaction with the quality and reliability of service provided by outside agencies.

7. Staffing Issues

- People have various needs that they hope to have met through their relationship with their attendant; a sense of control and respect are essential ingredients for a good consumer/staff relationship.

- People believe staff training could be improved, but there are sharply divergent opinions as to how this could be accomplished.

- Staff turnover affects the quality of service and is a source of frustration for both consumers and service providers.

- People want the option to choose whether or not they are involved in the hiring and firing of their own staff.

- There is a constant tension between service providers who are trying to schedule to meet everyone's needs, and consumers who want more individualized, flexible scheduling.

8. Direct Funding, Brokerage, and Legislation

- Most people support the concept of direct funding to the individual consumer (an Independent Living Allowance or ILA), which would enable the individual to have the option of hiring, firing, and supervising support staff. There are several other pieces of data which support more direct, individualized funding.

- There is strong support for consideration of the role of brokerage in the development of a comprehensive support system for people with physical disabilities. Brokerage can be described as a non-profit entity that provides a person called a broker to assist individuals in such areas as identifying needs, exploring community resources, and contracting support services.

- There is recognition within many sectors that a more coherent legislative base is needed to support the philosophy and framework for delivery of support services.

Recommendations:

Based upon the Review findings and analysis of lessons from other jurisdictions, forty-four recommendations were developed. These are grouped in the following categories:

(i) Principles and philosophies to guide policy and program decisions.

(ii) Strategic planning to assess proposed policy changes, to implement program recommendations, and to establish a long range plan.

(iii) Clear guidelines to assist in project implementation.

(iv) Research and/or demonstration projects in areas that need to be better understood.

The recommendations in total contribute to building a coherent framework for responding to the support service needs of adults with physical disabilities.

The recommendations are developed as part of the summary and analysis for each Chapter. They are then organized in the above categories as part of Chapter 11. This final Chapter proposes a series of strategies for follow-up to maximize the impact of this Review.

Chapter 1

INTRODUCTION

This comprehensive Review has several overall objectives:

- to determine the nature of the support services needed by physically disabled adults to assist them to live in the community.
- to review the Support Service Living Unit program and the Attendant Care Outreach Program.
- to assess the experience in other jurisdictions with various models of independent living assistance.
- to develop policy and program options for personal support services for physically disabled adults.

The Government's paper, *Challenges and Opportunities* (1986), describes a Multi-Year Plan related to deinstitutionalization and community living for people with developmental handicaps. This Review is the first step in developing a comparable thrust in the physical disabilities area. Although many questions remain about how this policy perspective might be developed, it is clear that this Review is the first time that all of the pieces related to support needs of people with physical disabilities have been looked at in a comprehensive manner.

BACKGROUND AND CONTEXT

The need which many physically disabled people have for support services has been increasingly linked to people's desire to live independently in the community. Independent living as a concept emerged out of the 1970s, a decade during which consciousness and acceptance of people with disabilities greatly increased.

The Charter of Rights and Freedoms enacted in 1982 further focused people's consciousness on the rights of citizens with disabilities. Disabled people were seen as having a right to equality and access through "reasonable" accommodation and support. Recent decisions of the Supreme Court of Canada have supported this framework for equality.

These developments, and government's interest in providing supports for people with physical disabilities to live more productively in the community, can probably be attributed to a number of historical factors including:

1. **The de-medicalization of disabilities, with the growing recognition that people with disabilities and handicaps are not sick but are developing person's who may need support to live in the community with dignity**. For decades, physical disabilities had been strongly associated with medicine and rehabilitation (De Jong, 1979). By 1981, however, the Federal Government's *Obstacles Report* reflected the shift from a medical approach to a social, political, and economic analysis of disabilities.

2. **The impact of normalization and integration as an ideology to guide service development**. Since the late 1960s, the principle of normalization, which emphasizes the value of people with disabilities having ordinary life experiences, has been the guiding philosophy for many human service jurisdictions. Normalization focused attention on the ways in which language, images, and programs can either enhance autonomy or maintain people in dependent social roles (Flynn & Nitsch, 1980; Wolfensberger, 1972).

   The emphasis on community integration during the last decade has led to a growing awareness of the barriers facing people with disabilities and the support that is needed for people to be equal participants in our society.

3. **The growth of the consumer self-help movement and its focus on human rights, full participation, and social change**. For disabled people in Canada, this movement has been spearheaded at the national level primarily by the Coalition of Provincial Organizations of the Handicapped (Derkson, 1981). The growth of local and provincial organizations of disabled persons in the 1970s created a forum for the discussion of significant disability issues. In 1980, at the World Congress on Rehabilitation International held in Winnipeg, consumer leaders from around the world presented papers on rights, self-determination, the consumer movement, consumer participation and social change (Miller et. al., 1980). By 1985,

COPOH had passed a number of important resolutions on independent living and had successfully promoted the initiation of Independent Living Centres. Two other national associations, the Canadian Association for Community Living and the Canadian Mental Health Association, have also recently been encouraging consumer participation by producing useful resource materials promoting independent living and consumer participation (Hutchison et. al., 1986).

4. **The thrust towards deinstitutionalization and community living alternatives.** Although the movement of people from institutions to the community has been neither systematic nor widespread in Canada, deinstitutionalization efforts in the 1970s raised hopes that community living could become a reality for all disabled persons. For people with disabilities, institutionalization has represented a loss of self-determination as well as isolation from the rest of society. Because deinstitutionalization has often come to represent independence and integration, the consumer movement and other advocacy groups have continually emphasized the need to reallocate resources for independent living from institutions to the community (COPOH, 1985; Church & Pape, 1987). Developing support services which encourage more independent living has been an important thrust of this work (Centre for Research and Education in Human Services, 1983; Lord & Hearn, 1987; National Institute on Mental Retardation, 1983).

5. **Changing Role of the Family.** With significant changes in family structures in society, it is no longer possible to expect that families will provide the kinds of intensive supports they have provided in the past. The increasing incidence of single parent families, transience, two working parents, and separation from the extended family (Vanier Institute on the Family, 1985), has forced individuals to rely more and more on formal services. While families continue to have a crucial role to play in the provision of informal supports, the changing role of the family has raised awareness about the need for more systematic, individualized support services.

6. **The increasing disillusionment with the service system model and the growing recognition of the importance of building community.** The expansion of human services in the last two decades has not been without consequences. Consumer groups and other advocacy groups have noted that many professionals and service

agencies are not accountable enough to the consumer. As some people's disillusionment has grown, alternatives have emerged which emphasize self-help, use of community, and individualized funding for support services. There has also been an increasing awareness of the problems of relying heavily on the service system to meet the majority of people's needs. In response, greater efforts are now being put on strengthening people's social support networks (McKnight, 1977, 1986; Snow, 1985), and on the development of mechanisms such as brokerage, which will enable agencies to be more accountable and responsive to the individual. (Attendant Care Action Coalition, 1987).

These trends from the past two decades have compelled the disability movement to look for better ways of promoting the independence of people with disabilities. The provision of support services at home and in the community has been a concrete response to this growing need.

THE CONCEPT OF INDEPENDENT LIVING

The need for support services for physically disabled persons must be understood in the context of independent living. Independent living as a concept has been concerned with quality of life, and the decisions one makes about one's life, not so much the tasks that the person can physically perform (Zola, 1982). De Jong (1979) initially defined independent living as a social movement but also as an analytical paradigm. Independent living was seen as a new paradigm because of its contrast with traditional rehabilitation. Canadian perspectives have generally incorporated these early American notions.

> The independent living concept provides consumers with an analytical framework for identifying and solving problems. From the paradigm, consumers frame questions of lifestyle and devise new solutions to lifestyle problems (COPOH,1986, p. 27).

The essence of the independent living philosophy is consumer control and choice within the community. In this sense, the concept of independent living in Canada is a political perspective.

> The I.L. concept at its heart has to do with self-determination and liberation for the individual within his society through collective self-determination and self-help by disabled people

> thereby (achieving) some power over their social environment (Derksen, 1986, p. 29).

The concept of independent living shifts people's thinking toward self-help, consumer control, and full participation in community life. This concept further suggests that problems and barriers faced by disabled persons are in the environment, not in the person (De Jong, 1979; Ryan, 1972).

HISTORY OF SUPPORT SERVICE INITIATIVES

While there is agreement among policy people in MCSS that services for physically disabled people have developed in a piecemeal, patchwork fashion, there is also consensus that the growth of the services in the last decade has been phenomenal.

A brief history of the development of services in Ontario will give a picture of some of these developments (Cheshire Homes Foundation, 1984; interviews with service providers and key informants).

- Prior to 1967, people with physical disabilities lived in chronic care institutions or nursing homes; with their families or friends; or alone, utilizing nurses or homemakers on a limited visitation basis.
- In 1967, a large residence for 61 people was built in Toronto, funded under the Charitable Institutions Act. Up until the early 1980s, this setting was filled to capacity. Between 1967 and 1972, the limitations of this kind of model started to be recognized.
- By 1973, several other smaller community alternatives known as Participation Houses were beginning to be developed, including a facility for 36 people which included a workshop, recreation facilities, attendant care, nursing, and parent relief; funded under the Homes for Retarded Persons Act. At this time, MCSS was also funding the development of smaller group homes (5-10) for people with developmental handicaps.
- By 1975, there was an awareness of the need to separate the housing component from the support service component, leading the way to the apartment or individual housing/support model. By this time, there was also a fair degree of publicity about young physically disabled adults.

Many were coming out of rehabilitation settings without any support or opportunity to reintegrate their lives into their communities. In addition, it had been shown that many people with physical disabilities in their 30s and 40s were living at home with aging parents.

- This growing awareness of physical disability issues, combined with extensive work within the Ministry, finally led in 1976 to MCSS agreeing to fund, as demonstration projects, four groups who had initiated their own projects five months earlier. These projects were all group residences, funded under the Charitable Institutions Act. They were set up in Windsor (Alpha), Thunder Bay (HAGI), Toronto (Clarendon), and Ottawa (Rehabilitation Institute). These fifty-two units were the beginning of what came to be known as Support Service Living Units (SSLU).

  These pilot projects were significant in the history of support services for people with physical disabilities because, for the first time in Ontario, money for the housing component (including rent supplement) came from Canada Mortage and Housing Corporation and the Ministry of Housing, while the Ministry of Community and Social Services provided the dollars for the support service component. This paved the way for the Ministry of Housing to be much more involved in providing housing for disabled people and other minority groups. It also meant that MCSS could focus more legitimately on the support service role.

  These pilot projects also, for the first time, enabled people with disabilities to receive their Social Assistance, Gains-D cheques directly from the government. This was a significant philosophical change because it recognized people's ability to manage their own money.

- The Homes for Retarded Persons Act, still the funding vehicle for some of the Participation Houses and other large facilities, has been a controversial piece of legislation in providing housing and support for persons with physical disabilities. In the early 1970s, it was the only piece of legislation which Ministers felt they could use to provide residential and support services for people with physical disabilities. The Act states that:

  > "Homes for Retarded Persons" means all or any part of a building maintained and operated by an approved corporation with a residential accommodation of retarded persons...

By the mid 1970s, the limitations of both the Charitable Institutions Act and the Homes for Retarded Persons Act were being noted by government. Both Acts utilize an 80/20 funding formula, and incorporate an institutional approach to service delivery.

- In 1976, almost all small group home funding for physically disabled adults was converted from the Charitable Institutions Act to the Ministry of Community and Social Services Act. The Ministry Act was developed as general legislation, permitting the Minister to:

> enter into agreements with organizations, municipalities or other persons or corporations respecting the provisions of social services and community services including items, facilities, and personnel relating there to upon such terms and conditions as may be agreed and he may direct out of money appropriate by the legislature the payment of such expenditures as are necessary for such purposes.

- In the early 1980s, MCSS began to fund the operation of SSLU projects 100 percent. This shift was accompanied by rapid expansion in the period 1983 to 1986. During this time, a broader range of consumers and services began to evolve, including more integrated, dispersed projects and the use of support services within selected housing cooperatives.

- In 1984, the Attendant Care Outreach program was introduced under the Ministry Act. The Outreach Program represented a policy initiative designed to address some of the needs in the community which were being expressed to the Ministry. Far more individualized than the SSLU projects, Outreach enables individuals to access an attendant up to 90 hours a month in their home. Area offices of MCSS have also approved service up to 120 hours a month.

- In the early 1980s, MCSS funded several requests from individuals who required extensive support to live in the community, and whose needs could not be met by existing programs. These Orders-in-Council provide individualized funding through an agency. The consumer then uses this funding to hire and direct attendants to address the individuals support needs. The Orders-in-Council now serve 13 individuals, while many of the individuals who were on the waiting list are now receiving some support through Outreach.

Chapter 2

METHODOLOGY

This Chapter describes the design and conduct of the research that formed the basis for this Review. The research process was developed to meet the objectives of the Review outlined in Chapter 1, and included the following steps:

- identifying the research questions that were to be used as the basis for the study.
- identifying and utilizing a variety of sources of data.
- sampling the sites and participants.
- analyzing and interpreting the data collected.
- developing coherent recommendations, an agenda for the future, and follow-up steps for Phase II of this Review.

RESEARCH QUESTIONS

The three questions that formed the basis of the study methodology are:

1. What are the needs of disabled persons for support services that are within the current or potential mandate of the Ministry?
2. What are the issues and concerns related to the province's two attendant care programs?
3. What relevant information or experience is available from other jurisdictions that would be helpful in improving support services?

Emerging Needs of Individuals

From an extensive review of the literature, we identified two levels of need which can be conceptualized. The first level might be considered *core needs,* which are common to all human beings. The next level of *functional needs* relates to one or more of the core needs. The difference between the two levels of needs is that functional needs are more individualized and are a direct function of the specific supports which people require for independent living. So, for example, a core need might be independence, while functional needs would include support in finding a job or assistance in getting to work.

Through a consultation process with twenty consumer leaders from across Ontario, a list of core needs was developed. The needs subsequently served as the backdrop for discussions on issues and concerns with study participants and formed the basis for the inclusion of functional needs in our survey. Below is a list of the core needs:

1. Financial security
2. Physical safety
3. Nutrition and health
4. Comfort and shelter
5. Independence and control over one's life
6. Relationships
7. Personal growth

Issues and Concerns

At the beginning of this Review, background information from MCSS had already identified a number of concerns and issues related to the province's two attendant care programs. This area of study focused on clarifying the issues already raised and on identifying new issues that emerged from our information data gathering phase. The major findings of the study came out of this issue analysis and created the framework for most of our recommendations and suggestions for future directions.

Other Jurisdictions

Literature and research on independent living, attendant care, and independent living centres form an important part of this Review. Other jurisdictions, such as community living for developmentally handicapped persons, or recent initiatives in aging or mental health, have also been studied in order to identify other models of service. These learnings are presented throughout the document, and incorporated into our broader discussion of the future policy options for MCSS.

SOURCES OF DATA

This Review was a research process; it was not a task force conducting hearings around the province. The complexity of this Review made it essential that the research process be designed to utilize a variety of sources of data. The sources of information utilized were:

- in-depth interviews with consumers, service providers, and MCSS staff.
- questionnaire surveys with consumers and attendants.
- selected demographic data from the Report of the Canadian Health and Disability Survey.
- community meetings held in eight communities throughout Ontario.
- research and program reports from a number of agencies, associations and communities.
- field reports and observations of selected SSLU and Outreach models.
- current legislation, program guidelines, and related MCSS policy documents.

A systematic plan was developed for gathering the information from each data source in the most valid and reliable manner. For example, the questionnaire survey was based on intial information provided by twenty consumer leaders. Our Advisory Committee, and the project advisors, also reacted to drafts of the survey and proposed alternative approaches where appropriate. Similarly, the qualitative interview guides were based upon the researchers' knowledge of the issues, the literature review, and input from the Advisory Committee. In addition, our first field visit served as a pilot site, and the interview guides were adjusted following that visit.

SAMPLING AND RESEARCH PROCEDURES

Several levels of sampling were required in this research design.

Eight communities in Ontario were selected to be the field sites for interviews with consumers, service providers, and MCSS program supervisors. These communities were carefully selected to represent regional and geographical differences.

Outreach and SSLU agencies within each of the selected communities were then carefully chosen to represent the range of service models (See Chapter 6). In the three communities where one agency had a monopoly on the attendant care services, such sampling procedures were obviously not utilized.

Once an agency was selected, they were asked to send the researchers a complete list of current consumers as well as individuals on waiting lists, identifying people only by initials, sex, age, and current service received. To decide who to interview and survey, a stratified random sampling approach was used. This allowed the researchers to select a range of ages and types of service recipients. For example, in an Outreach project serving 20 people with a waiting list of 18, 4 consumers would be selected to be personally interviewed, 8 consumers would receive the survey and 4 people from the waiting list would be chosen to be interviewed.

A similar stratified sampling procedure was used to select attendants to be surveyed from the lists of attendants sent from the agencies.

To inform people that they were selected to be interviewed, service providers were asked to hand a letter from the researchers to each individual. The letter clearly explained that the study was being conducted by an independent research group and invited people to participate in a personal interview. Similarly, surveys were handed out by service providers, with a covering letter noting that attendants were not to assist with the surveys being filled out. Surveys included a stamped addressed envelope for people to return their surveys.

In total, 176 consumers were surveyed, with a response rate of 63 percent. 174 attendants were surveyed with a response rate of 44 percent. A total of 175 people participated in individual or small group interviews. Finally, 363 people attended nine separate community meetings and shared issues and concerns related to support service needs. (See Appendix A for details of who was interviewed and surveyed.)

THE DATA ANALYSIS

The Quantitative Analysis

The data from the written surveys were descriptively analyzed, using frequencies and percentages. Table 1 presents the variables that were analyzed in the survey. A distinction was made between the SSLU and Outreach programs for both consumers and attendants.

The Qualitative Analysis

The qualitative data analysis did not begin with a theory or hypothesis to test. Rather, in the tradition of grounded theory (Glasser and Strauss, 1967), experiences, perceptions, and processes were analyzed to identify patterns, themes, and nuances of understanding. This process of inductive analysis produced patterns and themes in two ways. Some emerged directly from the participants, while others were noted by the researchers (Patton, 1980). As we shall see, with some issues that emerged in this study, the focus on individual perceptions created a sense of "multiple realities" (Wiseman, 1970).

The six steps of qualitative analysis include:

1. *Organizing notes from the interviews and the field with detailed quotations and observations.* Immediately after each interview, the researchers reviewed their notes, highlighted direct quotations and tidied up the interview notes. Brief field notes based on the researchers' observations during the interview were also made.

2. *Summarizing the data from each site according to sectors.* For example, the consumer interviews from one site were summarized as a group according to the research questions. Summaries included the number of consumers who express a particular viewpoint with accompanying quotations and summary comments.

3. *Coding the data by needs, issues, satisfaction, impact and future alternatives.* This was accomplished on a site-by-site basis for all sectors (consumers, consumer leaders, service providers, and regional

MCSS representatives). Coding is a process of attaching key words or phrases to interview data as a way of identifying commonalities and variations in the data.

Table 1

Variables Examined in Survey

- consumers' level of satisfaction with their attendants' training and approach to work
- consumers' level of satisfaction with different aspects of their support services program
- consumers' thoughts on how the program could be expanded to allow for a more independent living situation
- areas where consumers would like more control and direction in services and in their lives in general
- consumers' thoughts on future directions
- attendants' perceptions of consumer needs that are or are not being met by the particular support system
- attendants' level of satisfaction with their current training and thoughts on future training directions.
- attendants' level of job satisfaction
- attendants' thoughts on how the role of attendant services could be expanded.

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4. *Identifying common and variable patterns for all sectors within four sites for all sectors.* This was done after the data was coded. Based on the codes, we looked for the major issues and sub-issues. At this stage, we noted both the majority views and the minority views.

5. *Comparing patterns and differences across sites and across sectors.* After four sites were coded and analyzed, we identified the key themes that link or explain the data. The major issues and sub-issues were collapsed under four broad themes, and summaries were written of people's needs, sources of satisfaction, impact, and future alternatives. The four remaining sites were then used to determine if the data validated or repudiated our initial findings.

6. *Re-assessing the major themes of the Review and the sub-findings.* Based on the complete coding and analysis of data, the initial framework was re-worked to highlight key findings and to present the data in a concise manner.

Chapter 3

MEETING CORE NEEDS ESSENTIAL TO DEVELOPING SUPPORT SERVICES

In designing this Review, we identified a number of core or basic needs which a review of literature revealed are fundamental to all human beings. In our survey and interviews, people were asked the degree to which they feel their core needs are being met.

The important finding of this study is that people very much see their major issues and problems in their lives as being related to one or more of their basic needs being unmet. This results in situations where it is difficult, if not impossible, for people to feel any real sense of control over their lives.

The three major findings from our analysis of needs are:

1. ***Many individuals with disabilities, because of the extensive barriers and lack of supports in their lives, identifiy a number of unmet basic or core needs.***
2. ***Independence and control are the unmet needs predominantly identified by people with physical disabilities.***
3. ***There is wide individual variation in the areas consumers identify which they believe will assist them in having more control and independence in their lives.***

CORE NEEDS UNMET

As noted, we all share the same fundamental needs. The difference, for people with disabilities, lies in the number and types of barriers that are encountered in trying to fulfill those needs. In this section, people talk about their need for economic independence, comfort and safety, nutrition and health, and personal growth and relationships.

The Need to be Economically Independent

In this era where national unemployment is relatively high, and foodbanks have become an entrenched institution, it is widely acknowledged that there are many people in our society who are without resources, and living below the poverty line. Financial security is essential to personal freedom; without this, people have very little control in their lives. In this Review, the major finding is:

> ***People are extremely relieved to be free of the financial responsibility of paying for their own attendant; however, in the majority of cases, people's economic status remains unchanged.***

Financial Security Improves with Free Support Services. It is clear from personal interviews that people recognize that the fully subsidized services offered by the SSLU and Outreach programs remove a large financial burden from their shoulders. (Service Providers: Outreach & SSLU. Consumers: Outreach & SSLU). This is particularly true for people living in SSLU projects where rent is geared to income, whereas the same opportunity is not always available to people living in the community receiving Outreach. Despite this fact, all consumers, SSLU and Outreach, express their satisfaction at feeling more financially secure because their attendant care costs are fully covered.

For some people, the support services allow them and/or their spouse to return to work (Consumers: Outreach), and to lead a more active life generally. (Consumers: Outreach & SSLU)

> *"We feel more financially secure because my wife is free to go out and work. Before she had to care for me and we only had my pension and some Workman's Compensation. We had only $100 left after paying the mortgage." (Consumer: Outreach)*

> *"It was never intended to make you feel financially secure. However, before living here I would have to live in an institution and now I have my own funds for my own needs and can afford to go out." (Consumer: SSLU)*

Underlying Conditions of Poverty Do Not Change. Although consumers appreciate the subsidized attendant care services, the reality is that many people with disabilities are impoverished. (Service Providers; Consumer Leaders; Consumers: Outreach & SSLU; MCSS staff).

Many other people are unemployed and surviving on Family Benefits Allowance/Gains-D. The survey shows that 18.5 percent of the respondents are employed full-time, 18.5 percent are employed part-time, and 62 percent are unemployed. When survey participants were asked to identify the factors which would provide them with more independence and control in their lives, it is not surprising that 77 percent of respondents indicate that the amount of money they have is 'important' or 'very important' to achieving more control. (Please refer to Appendix B for complete Table).

Our findings are substantiated in a report from the Secretary of State of Canada (1986), where it was noted that 52 percent of people with disabilities were not in the labour force, compared to 25 percent of the non-disabled population. Furthermore, 63 percent of people with disabilities receiving some form of individual income earned less than $10,000 annually. These figures are based on the 1983-1984 data collected by the Canadian Health and Disability Survey conducted by Statistics Canada. It is important to point out that the survey sample was based on households, and did not include people with disabilities living in hospitals, chronic care facilities and nursing homes.

The following comments from individuals who were interviewed help to illustrate the economic hardship that many people experience.

> *"You can get used to doing without, but you are always a second class citizen because you have no money for clothes, to go to a show or to eat well. As a result [of no money] you have a poor sense of your own value. Although the consequence of no money is indirect, it affects your entire life and entire sense of self." (Consumer: SSLU)*

> *"I don't think that the system is designed to make you feel secure financially...the pension is made to maintain you...there's a difference." (Consumer: SSLU)*

There are other factors, mentioned in interviews, which contribute to the poverty experienced by a number of people with disabilities: income maintenance is not tailored to meet people's individual needs, but is instead part of the welfare system; accessible, affordable housing tends to be in short supply; the labour market is still not very receptive to or supportive of people with disabilities; people who have been institutionalized for long periods may have never had the opportunity to develop their vocational skills; and the cost of medical supplies or technical aids can be prohibitive.

A recently published study by the Coalition of Provincial Organizations of the Handicapped (1987) highlights the fact that many disabled people on social assistance experience a triple jeopardy. Systemic discrimination hinders people with disabilities from obtaining good jobs; social assistance rates are low in the expectation that people will look for work; and the low rates must cover everyday living expenses plus the extra costs associated with a disability.

Comfort and Safety

The need for security is often mentioned as a core need for all people. While the need for security can be met in varying ways, feeling and being safe in one's surroundings is an important aspect of security. Our major finding is that:

> ***People with physical disabilities have a lot of concerns about their personal safety.***

Consumers who responded to the survey ranked "feeling and being safe" as one of the top three areas where they want more independence and control. People identify several factors that contribute to concerns about their personal safety. Each of these will be briefly discussed.

Fear of Not Being Able to Get Help. Many consumers in both SSLU and Outreach indicate they worry about being alone and not being able to get help when they need it. For vulnerable adults, this is a particular problem:

> *"Sometimes I get scared that I am going to fall and hurt myself and that I will be there all day. I have a speech problem so I can't yell out." (Consumer: Outreach)*

> *"If there was a fire and everybody panicked, how would they help me? At night I have my hearing aid out so how would I hear the alarm? There are 25 disabled people in the building and 2 night staff." (Consumer: SSLU)*

Consumers receiving Outreach in their own home are particularly concerned about the safety, and some people clearly limit their activities as a result.

> *"In moving here I am less risky in what I do and don't do ...at home I had my family to help me up if I fell...here I would have to wait 8 hours before being picked up." (Consumer: Outreach)*

Interestingly, the survey shows that more SSLU consumers want increased independence and control in the area of "feeling and being safe", as compared to Outreach consumers. While this may seem surprising, given the 24-hour back-up support, perhaps people do not feel control over that support. The following quote reflects this concern:

> *"The more responsibility someone has for your safety, the more you give up your control and the more institutionalized you would become." (Consumer: SSLU)*

Uncertain Staff Support Reduces Safety. People with disabilities who need physical support in daily living are often highly dependent upon staff, family, and friends. Consumer concerns about personal safety are clearly related to their level of confidence in their staff support.

> *"My attendant didn't believe me (about how I needed to be moved) and then I got dropped. That means they need to listen more and be better trained." (Consumer: Community Meeting)*

Outreach service providers are conscious of the need for safety, and some organizations insist that the consumer have a back-up system in place. Consumers that have no back-up may be denied services.

> *"We can't take on consumers who don't have a back-up in their own home. We have to know that when an attendant is not at the person's home, someone else will be in the house. We just can't take any chances." (Service Provider: Outreach)*

As an interesting alternative, there are independent living centres that are teaching consumers how to develop peer support safety networks.

Inaccessible Housing Reduces Comfort. It is difficult to know how many people are living in settings where the bathrooms are not large enough, or the counters are not low enough, or the assistive devices are not available. People talk about having to take sponge baths because their bathrooms are not accessible. One man (Consumer Leader) lives in an apartment where only one of the two bedrooms has an accessible doorway. That means he can never go into his children's bedroom to say goodnight or to wake them up in the morning. Consumers emphasize that all of this creates an element of unsafety and detracts from a person's comfort.

> *"Since my place is not accessible in any way, I don't feel safe. But that's the risk I'm willing to take to be independent from my parents." (Consumer: Outreach)*

This perspective supports other Ontario research which shows that fairly high percentages (20-50 percent) of people with disabilities desire housing which supports them to live more independently (Hamilton Social Planning and Research Council, 1986; Waterloo Region Social Resources Council, 1985).

At first glance this may appear to be a housing issue that does not tie directly into the SSLU and Outreach programs. However, as consumers and service providers note:

> *"You cannot approach this as one problem; it is a set of inter-related problems. If the housing were better, you would need less attendant care." (Consumer: Outreach)*
>
> *"You can't begin to predict how many attendants you'll need in the future without knowing the type and amount of housing that will be available then." (Consumer: Community Meeting)*

Without a more generic approach to building accessible housing, combined with tough enforcement of existing regulations, the options for consumers remain limited. One person comments :

> *"Feeling safe should not mean being required to be segregated in a SSLU complex." (MCSS staff)*

Access to Assistive Devices. In terms of responding to the need for comfort and safety, the survey data support the views of the interview respondents, who in general believe that:

> *"Sometimes all that is needed is a simple lifting device - we need more funding and support for appropriate technology." (Consumer: Outreach)*

In this era of technological devices, the solutions should be relatively simple. Nevertheless, over one-third of the survey respondents who already rely upon one or more assistive devices indicate the need for more and better quality technical aids to make their homes safer and their lives more secure. As examples of devices that could enhance a person's feeling of security and freedom, people mentioned: Protect-A-Lert, remote door operators, warning lights instead of bells (in specific cases), and hoyer lifts.

The Right to Risk. Some consumer leaders point out that the need for security should be balanced against a person's wish to live their own life, even if it means taking a few risks. According to several consumer leaders, safety has been used in the past as an excuse to restrict individuals with a disability. Although professionals may argue that they have a certain legal responsibility, the statement of one consumer is telling:

> *"I'd sooner die in my apartment on my own because of a fall than be forced into a protective institution. The consumer is willing to take the risk." (Consumer Leader)*

Nutrition and Health

During the last 10 to 15 years, there has been a remarkable increase in the general public's awareness of healthy lifestyles and well-being. With the emphasis on keeping fit, eating nutritiously and discontinuing habits such as smoking, the tendency has been to assume that individuals are primarily responsible for their own health. By assuming this, however, the fact can be overlooked that people do not always have control over the socio-economic and environmental factors which can undermine their health.

The major finding is:

> ***People believe that they should be responsible for their own nutrition and health, however, certain limitations in support services can detract from their efforts to maintain their health.***

Personal Responsibility Entails Personal Control. Service providers tend to emphasize that a person's health and nutritional status is a matter of individual lifestyle and personal responsibility. (MCSS staff; Service Providers) While there is a minor watchdog role to be played, especially with respect to skin breakdown, the ultimate responsibility rests with the client.

> *"If the client is poorly nourished or if the family is not feeding the relative well, we are limited in what we can do. The care is supposed to be self-directed. We don't take control of their lives." (Service Provider)*

> *"If we go into someone's home we cannot force them to eat properly but we can observe their eating habits, discuss with them good eating habits. If their eating is poor, the support care worker documents this and reports it to the program supervisor who completes a Health and Safety form." (Outreach Service Provider)*

Some service providers indicate that consumers do not always assume responsibility for their own health. (MCSS staff, Service Providers)

> *"They have a tendency towards infection and sometimes you have to hound them to see a doctor." (Service Provider: SSLU)*

At first glance, the survey findings suggest that consumers would agree that they are ultimately responsible for their own health. Fifty-seven percent of the respondents indicate that having more control over what they eat is 'important' or 'very important'. However, analyzing the findings from personal interviews, we realized that people were not necessarily talking about personal responsibility for their health; sometimes they were talking about having more control over the service constraints (such as tight scheduling) that prevent them from eating well.

> *"We do our own grocery shopping but we are only allowed 1/2 hour of attendant help in the preparation and clean up of meals. You end up eating only frozen food because of no time for preparation. You can't eat healthy meals because if it takes the staff 10 minutes to peel a potato then there is only 20 minutes left to cook and clean up." (Consumer SSLU)*

> *"You only eat nutritionally if they show up. Otherwise you don't eat at all." (Consumer: Outreach)*

Inequities in Health. Earlier it was noted that a significant number of people with physical disabilities are unemployed and dependent upon social assistance. This has a definite impact on people's health. Repeated epidemiological studies have demonstrated a direct correlation between a person's socio-economic status and their health. One of the most recent reports to document this finding is the *Active Health Report*, produced by Health and Welfare in 1987.

In the report, which was based on a health survey of 11,000 adult Canadians, the authors note that low incomes compromise people's health by making it impossible to purchase nutritious food, decent housing, and the other necessities of life. Furthermore, disadvantaged Canadians - those with lower incomes, less education, and no employment - are three times as likely to rate their health as poor than people in the highest income group. They are also less likely to feel that there is something that they can do to improve their health. According to the Health Report this is probably reflective of the fact that low income Canadians are more likely to be exposed to environmental and socio-economic factors that undermine their health.

Personal Growth and Relationships

People interviewed and surveyed emphasize the importance of a range of relationships and opportunities in their lives. A major finding in this study is:

> ***A small majority of the people have concerns around their opportunities for personal growth and relationships.***

Consumers in the survey were asked if they wanted more control over their lives. Their responses to the four items which were related to personal growth and relationships are shown in Table 2.

It can be seen from these results that many people want more opportunities to experience strong relationships and personal growth.

Isolation. A number of people who were interviewed feel isolated from friends, family and community. (Consumers: Outreach, SSLU & Waiting List; Consumer Leaders). For a few, the isolation and loneliness seem to be unrelenting:

Table 2

Consumer Perceptions of Areas Where More Control and Independence are Needed for Personal Growth and Relationships

Area	O.K. As is %	Less Impor. %	Impor/Very Impor. %	N %
Who my friends are	30	4	66	100
Seeing my friend	28.6	2	69.4	98
Involvement with family	28.3	9.1	62.6	99
Going to school/learning opportunities	23.7	29.9	46.4	97

> *"Even though it's nice to have your own apartment, if you can't get out then the walls get smaller and you really are isolated." Consumer: SSLU)*

> *"I had to move away from my friends and family. I hardly ever get to see them and I really miss them. I would like to live closer so we can visit at least." (Consumer: SSLU)*

Others feel that this sense of isolation is compounded by the attitudes of the community surrounding them. If people at work, or on the streets shun individuals with disabilities, this can only serve to create a barrier in forming relationships with other people, thus contributing to their loneliness and isolation. (Consumers: Outreach)

> *"I've had a hard time relating to people in the community. I am the only quadriplegic in the area. There needs to be more public education in disabilities." (Consumers: Waiting List)*

> *"I lost all my friends when I had to quit my job. They all see me as a contagious disease." (Consumer: Outreach)*

Some people feel that the stuctures of the support services actually inhibit relationships from developing.

> *"In one way the program makes it hard for me to have friendships. If I go out with my roomates, then I have to rely on them to put me to bed. That's OK now and then but not all the time. If I want my attendant to help then I can't go out with my friends. How could I possibly have a girlfriend? Most nights 10 or 10:30 is OK but not all the time. This is putting a strain on my relationships with my roomates. They get uptight because they have to do too much and I get bitchy because I can't get out." (Consumer: Outreach)*

> *"You really don't have independence when you are isolated in your apartment and nowhere to go because no attendants are available." (Consumer Leader)*

On the other hand, some people feel that it is easier for them to get on with their relationships, now that they are able to live on their own, away from the confines of projects or institutions, and with attendant care. (Consumers: SSLU & Outreach). A service provider summarizes this perspective:

> *"Because they have more control of their schedule they are able to go out more. They have moved out of the institutions and therefore have more opportunities for personal growth and relationships." (Service Provider: Outreach)*

INDEPENDENCE AND CONTROL MAIN THEME

The second major theme that has emerged from this entire study is that the issue of independence and control permeates almost every area of people's lives. In other words, people constantly connect the issue of control and independence to their core needs. This reference to control is not always overt, but is usually the underlying reason for wanting a change.

The major issues around control and independence seem to be: 1) people's fear of continuing or future (re)institutionalization and, 2) people's desire to have input into the decision-making process at several levels. We shall briefly discuss these findings.

Fear of Institutionalization

In many respects, people are very pleased with the independence and freedom that SSLU and Outreach allow them in their lives. (Consumers: SSLU, Outreach; Consumer Leaders; Service Providers; Community Meeting). They are more independent of family supports and relieved to be out of an institutional setting. These positive impacts will be discussed further in Chapter 4.

Despite their feelings of appreciation, people also recognize the inherent irony of their situation - the more you depend upon services to provide you with your independence, the greater your reliance and the less your independence.

> *"Their lives and independence are totally in the control of the services that are supposed to be there to make them more independent. They work against you." (Consumer Leader)*

> *"We accept SSLU because it is our only way to avoid institutionalization. You have to take what you are given, because there are so few options." (Consumer: SSLU)*

The ongoing fear of institutionalization perhaps most strongly personifies people's perceived and/or real lack of control over their lives. For people with higher needs, or progressive diseases, this fear is well founded, for even small changes in economic status, physical condition, or staff schedules could result in hospitalization or institutionalization. (Consumers: Outreach and SSLU. Service Providers: Outreach).

> *"I was a victim of an institution. Just the thought of having to return makes me crazy." (Consumer: SSLU)*

> *"If my needs get too much greater, I would need more help. I want to stay here at home rather than be in an institution, but I don't want my wife to have to shoulder any more than she has now. But nobody has really explained what my options are for the future." (Consumer: Outreach)*

> *"There is a large problem with our clients having single aging parents. The parents are still trying to provide support, but the person always has to worry about their parent's health and the dreaded fear of institutionalization once the parent dies." (Service Provider: Outreach)*

Levels of Control

There are several areas where peole feel that if they had more control, they would also have greater independence in their lives.

At the most fundamental level, people mention they are constantly having to ensure that they have more control over their personal supports through their daily interactions and negoatiations with attendant care staff. One of the most important things for Outreach and SSLU consumers is to have support staff who understand and appreciate how the individual wants things done.

The next level of conrol for people who have the energy is achieved by being involved in hiring, supervising, and managing their own support staff. Ideally this should eliminate the problems associated with personality conflicts, personal scheduling, and ambiguity around the question of who is in control.

At another level, some people wish to be involved in the decision making that occurs within an organization or project. Many people emphasized that a strong consumer voice is mandatory when service providers are making decisions about people's lives.

Finally, for a few people, the voice of the consumer goes beyond their particular project or service, and they have become strong advocates in the movement for independent living. For these people, the ultimate form of control is based on influencing change.

Because of its predominance, this theme of independence and control weaves itself throughout the rest of this Review.

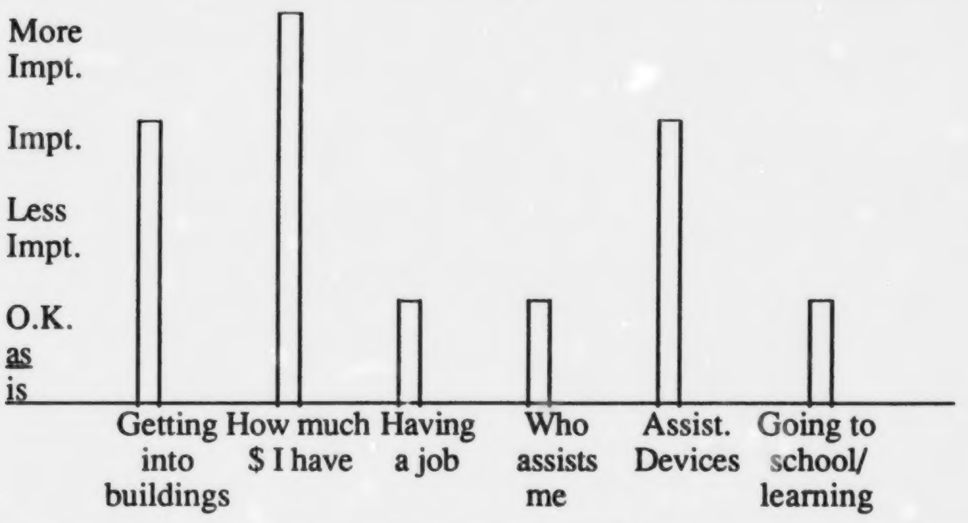
INDIVIDUAL VARIATIONS IN NEEDS

In the last Chapter, it was noted that everyone has distinct functional or individual needs which arise out of the core needs. The data show that there are wide individual variations related to meeting core needs.

While some people indicate a strong desire to have more control in the area of finances or where they live, others put more emphasis on having a job or involvement with family. Despite the fact that we all share common needs, each person's story is unique. The individual variations can be illustrated with the following case examples from our survey.

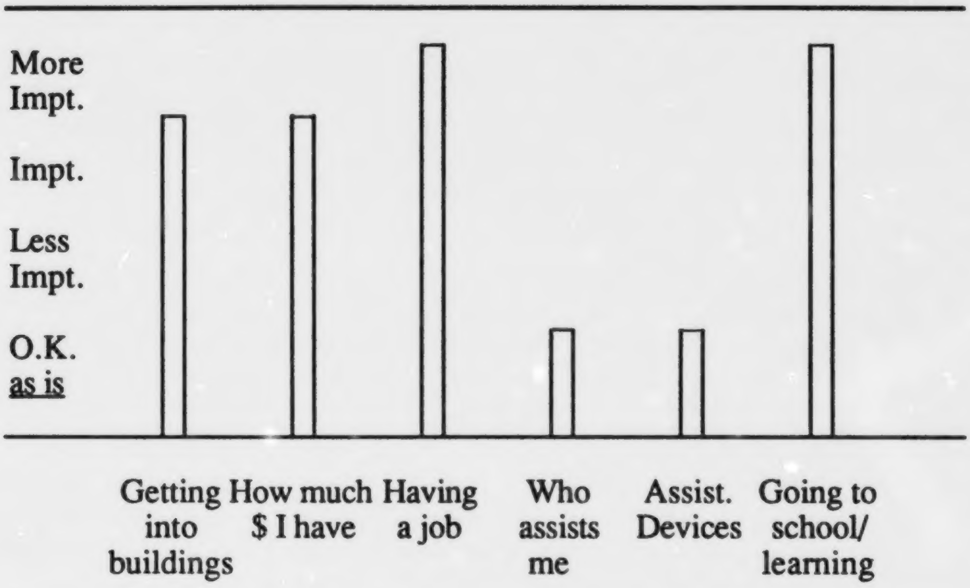
Case Study 1

Ms. Brown is 42 years old. She lives alone in her own home, where she receives eight hours of Outreach each week. She is employed full time, but is worried about keeping her job because of the deteriorating nature of her disability. She manages adequately with her current supports, but because of her condition, has requested additional support. She identifies a number of areas where she feels her needs could be better met if she is to have more control and independence in her life, as illustrated in the following profile.



Case Study 2

Ms. Green is 21 years old and lives alone in a small apartment unit which is part of a segregated SSLU apartment project. She does not have a job, and feels that more education is an important need for her. She manages at home with her current support but has little involvement in the community. She identifies a number of areas where she feels her needs could be better met if she is to have more control and independence in her life.



SUMMARY AND RECOMMENDATIONS

The analysis of consumer needs in this chapter has important policy and program implications. First, many individuals with disabilities identify several core needs which they cannot meet completely on their own. While some of these findings have been noted in other research studies, it has been important here to link these core needs to people's functional needs. For example, the fact that many disabled people are unemployed or poor significantly limits their options in terms of housing and other lifestyle decisions. Also, the core need we all have for relationships and social contact can be severely hindered by limited or restricted support services. People simply cannot get out to meet other people or participate in their communities.

In addition, however, it must be recognized that attendant care support will not address all the core needs of physically disabled people. For example, a related pressing concern of many consumers is the need for a more equitable income supplement system. It is hoped that the Social Assistance Review currently being undertaken for the Ministry of Community and Social Services will make comprehensive recommendations in this area.

Further, many people live in institutions; many others live with the fear of being institutionalized; and still others technically live in the community, but because of limited support continue to feel institutionalized. All of these situations make it difficult for people to feel control over their lives and to have their most basic core needs adequately met. As shall be discussed further in Chapter 6 on "Models", the more segregated and isolated a service, the less potential it has to meet core needs.

Based on our data and analysis of core needs and support services, it is recommended:

1. **That the Ministry develop a philosophy and framework to guide its support services in Ontario that acknowledges that the core needs of physically disabled people are the same as the core needs of non-disabled citizens; and that this philosophy be used as the basis for designing support services which are community-based and non-medical in their approach.**

Second, data from several sources point to the need for support services to be tailored to the individual. The strongest theme from the needs data, people's desire for more control and independence, supports this emphasis on individualized services. The other compelling piece of data is the finding that there is wide variation among consumers in terms of the areas they believe would give them more independence and control. Services which are not individualized, of course, fail to give credence to the variation of consumer needs and capacities. It is therefore recommended:

2. **That the philosophy and framework guiding support services in Ontario recognize that each person's core needs will be met in different ways; and that supports**

for independent living be provided in an individual and flexible way, reflecting this cornerstone principle.

Chapter 4

IMPACT ON INDIVIDUALS AND FAMILIES

The MCSS support services for people with physical disabilities, Outreach and SSLU projects, are having a tremendous impact on people's lives. In this chapter, we present the positive impacts of these programs. The five Chapters that follow this impact Chapter will include people's issues and concerns, including negative impacts.

Many people interviewed talk very dramatically about the positive impact that attendant care services have had on their lives. People refer to: changes that have happened in their own personal lives; the impact on their families; and their hopes for achieving future goals.

In our analysis of the impact data, three primary findings emerge:

1. ***People believe that the support service programs have contributed to their personal development, enhanced their lifestyles, and facilitated their independence.***
2. ***There is a sense of enormous relief shared by many individuals and their families because the burden of providing support has been lightened or removed.***
3. ***Having experienced some positive changes in their lives, many people are thinking about future dreams that they would like to fulfill.***

IMPACT ON PEOPLES' LIVES

Most service providers and individuals emphasize the fact that the support service programs allow people to either come out of the institutions, or to avoid being re-institutionalized. (Consumers: Community Meeting, SSLU & Outreach. Service Provider: Outreach; MCSS staff)

> *"I lived in an institution...For the first time in my whole life I now have my own bathroom, I can choose my own meals, I can have my own friends in and close the door. Now I have a job and work on a contract basis." (Consumer: Community Meeting)*

> *"In every way it has affected our lives. What would we have done if my mother was the only person to help me. I would have to be in an institution. This is my home, our home." (Consumer: Outreach)*

People also talk about the impact that the program has had on their personal growth and development.

> *"It was just a blessing that I was able to move into the SSLU project and it's been great for me ever since as far as improvement and being able to do what I want to do, and living the most independent life that I'm capable of doing." (Consumer Leader)*

> *"I think I learned more here in one month than I ever learned in the hospitals. They're not set up properly at all." (Consumer: SSLU)*

Finally, most people point to the fact that their lifestyles are changing for the better. (Consumers: SSLU & Outreach. Service Providers: SSLU & Outreach; Community Meeting). In some cases, this means that people have been able to return to work or school; in other cases, people have had greater freedom in pursuing friendships and their own interests. Ultimately, people are experiencing a fundamental change in their level of independence.

> *"Outreach enables me to have a job, and to play a viable and productive role in the community." (Consumer: Outreach)*

> *"I think I see more of my family than when in the hospital... I feel I can do the things that I want to do without interference. If I have visitors, they can stay for a couple of days." (Consumer: SSLU)*

> *"I feel like I'm in charge of my life now...I've grown to the point where I'm in charge not only of my life but my son's life. I've grown up a lot...I like having independence, the responsibility and the privacy." (Consumer: SSLU)*

IMPACT ON THE FAMILY

In general, the attendant care programs are having a very positive impact on families. In order to understand the extent of this impact, it is useful to note that in the Ministry's *Evaluation of the Outreach Attendant Care Program* (1986), 65 percent of the clients surveyed had been dependent upon a family member for personal assistance prior to receiving Outreach. Now, with support services available through both Outreach and SSLU projects, families feel the impact in several different ways.

A Reduction of Guilt

Families often worry and carry a lot of guilt, either because of their family member's disability or because they feel they can never do enough to help (Turnball et. al., 1985). Many consumers emphasize that Outreach and SSLU projects assist in relieving much of that guilt. (Service Provider: SSLU; Consumers: SSLU & Outreach; Community Meeting).

> *"After my accident there was a lot of fear. Now my family feels quite pleased; a lot of guilt has been lifted off their shoulders. I am completely in control of my wits in every decision I make. It's something my parents understand, my need for privacy and control, but my need to be cared for." (Consumer: Outreach)*

> *"My kids don't have to worry about me now. They are living their own life and they know how to get ahold of me if they want to see me. That's how it should be." (Consumer: SSLU)*

> *"My parents are relieved to see me having a better life. My wife and I can get along well and when she goes to work she knows that I have someone in the building." (Consumer: SSLU)*

The Support is Needed

It is widely acknowledged that the impact of the program on family relationships is very postive. As additional supports become available, families feel a great deal of relief combined with a reduction of stress. With people feeling more free, family dynamics improve. (Consumers: SSLU & Outreach; Consumer Leaders. Service Providers: SSLU & Outreach; Community Meeting).

> *"My sister has noticed the change. She could never just visit me before. I always had a list of things for her to do." (Consumer: SSLU)*

> *"We lived in our house and I know that it really frustrated my husband seeing me trying to fix the plumbing, fixing the toaster, and shovelling the snow and caring for him - now we get personal care help." (Spouse: Outreach Consumer)*

> *"I don't think my husband realized what a strain it was to have me unwell until the attendant started doing all the things that he had to do for me. And now we have more quality time together." (Consumer: Outreach)*

As many people readily acknowledge, prior to receiving support services, relationships tended to suffer when one member of the family was forced to depend upon another for personal care. The words of one man currently on the waiting list testify to the strain that marriages can undergo if attendant care is not available to assist with meeting people's basic needs.

> *"My wife can't participate in this process. She is not a nurse of chronically disabled people. That was not in the game plan when we married. She has rallied to me now, but we have to get it sorted out real soon or it's going to have a terrible effect on the marriage." (Consumer: Waiting List)*

The Importance of Prevention

Attendant care plays a critical preventative role. People note that when support services are available, there are fewer family breakdowns and relationships improve. (Service Provider: Outreach. Consumers: SSLU)

> *"I finally have a mother/daughter relationship now that I am in an apartment and on my own. For the past five years, it was war at home and my mother resented me being there. She is 73 and getting too old to care for my physical needs. Now when she comes to visit, the strain has lifted." (Consumer: SSLU)*

> *"A number of situations have occurred with Outreach that have avoided family breakdowns; the spouse is relieved of support duties which allows the individual to have a more fulfilling life*

> *as well as being able to focus on the relationship in a typical way rather than in the attendant capacity." (Service Provider: Outreach)*

When the family caregiver is not tied down to the home anymore, it allows the parent or spouse to go back to work and begin to meet his or her own personal needs. (Consumers: Outreach; MCSS Staff)

> *"This gives my wife a break from me, so she can go out and work. Before we argued much more. Now she has more time and flexibility and doesn't feel as bound. Before all she felt good for was supporting me." (Consumer: Outreach)*

> *"It has been a liberating force for my family...my immediate family and my secondary family. It has allowed my wife to return to school and work without feeling that she has left me feeling helpless." (Consumer: Outreach)*

The goal of supporting families in order to prevent family breakdown and to promote family stability and independence has been strongly endorsed in the Ministry's *Corporate Plan* (1987). The function of attendant care is consistent with the themes that are woven throughout the *Plan's* objectives and strategies:

- the role of social services is to support, not replace, individual and family efforts, so that self-help, not dependency, is fostered;
- the focus of social services should be on integration to help ensure that normal bonds are maintained in the home, neighbourhood and community. (MCSS, 1987, p.12).

THE IMPACT ON PEOPLE'S EXPECTATIONS

While people are generally pleased with the initial impact of their current support services, a related impact emerges from the data. When people are receiving a limited amount of support, they begin to realize the potential benefits of more support. On the one hand, this demand may be viewed by service providers and funders as an insatiable appetite that can never be appeased. On the other hand, the demand reflects the fact that people's expectations for their lives are changing. Having seen the impact that attendants have had in their home life, many individuals note the merits of having support in other areas of their lives.

When people were asked about their dreams for the future, they mention a desire to travel, to go camping, to return to school, to have a stable job, to attend workshops and educational events, to be able to live in a house of their own choosing, and to determine their own lifestyle. (Consumers: SSLU & Outreach). These expectations are not unreasonable; they represent the dreams and basic needs that we all share.

SUMMARY AND RECOMMENDATIONS

All three findings that were identified at the beginning of this Chapter have important policy implications.

First, people are pleased that the support they receive allows them to live independently of families and institutions. For many consumers, this has had a positive impact on their personal growth, lifestyle, and ability to integrate into the community through work, school, friendships, and community activities.

Policy options must continually recognize the importance of assisting people to live within their communities with as much independence and dignity as is possible. The *Corporate Plan* of the Ministry states that its primary goal is to *assist* communities to respond to the needs of families and individuals "in ways that reinforce personal dignity and independence" (p.8).

Given the above analysis and the positive impact that support services have had on individuals' lifestyles and independence, it is recommended:

3. **That attendant care services be designed with the goal of relieving family and friends of the major responsibility for providing support services, thereby reducing disabled persons' dependence on their family and friends.**

Second, given the significant impact that support service programs have on family stress and interpersonal dynamics, it is apparent that these programs are integral to fulfilling the stated goal of MCSS of supporting families and individuals in maintaining their independence and dignity (MCSS, 1987). It is also apparent that the concept of prevention, which

MCSS claims, "*is being incorporated as a significant consideration in program development*" (p. 12), is a working reality in support service programs. Many consumers mention the improvements they are experiencing in marital and family relationships as a result of having outside support. Alternatively, as presented in Chapter 5, the majority of individuals on waiting lists for Outreach describe how the lack of support is taking its toll on their marriage or their relationships with children, parents, and friends.

The United Nations, in its *World Program of Action Concerning Disabled Persons* (1983), claims that community services should make every attempt to prevent the separation of disabled persons from their communities and families. The findings in this study are also supported by the perceptions of the Ontario Advisory Council for Disabled Persons in their Discussion Paper on Independent Living Assistance entitled *Independent Living-The Time is Now* (1988). In their document, the Council claims that families should not be expected to provide full assistance to a disabled family member. Not only can this create a financial burden, but it can also prevent young adults from developing essential life skills. In the extreme cases of family stress, the result could be neglect and inappropriate institutionalization.

Based on our Review data and the preceeding analysis it is recommended:

4. **That individualized support services be recognized as playing a critical role in reducing individual and family stress, and that budgetary allocations to these programs reflect their key function in prevention.**

In the process of receiving attendant care, people begin to appreciate how much more they could accomplish in their lives if more of the appropriate kinds of supports were available. The emphasis in these discussions is not just on receiving more hours of attendant care, but on expanding attendants' functions in order to further individuals' integration into the community. People, quite naturally, would like to be able to choose their own lifestyles and pursue their own personal dreams. This notion of the potential of a second wave of impact requires further thought and planning.

In light of the above analysis, it is recommended :

5. **That the Ministry recognize that the current support programs have limited impact because they respond to**

only a portion of individual needs; and that to move beyond this initial level of impact, a more comprehensive plan capable of responding to the broader needs of individuals be developed.

6. **That a comprehensive plan for responding to the broader needs of individuals include both an individual planning mechanism and the option of individualized funding.**

Chapter 5

SUPPORTS AND SERVICES LIMITED

The focus of this Chapter is on people who require support services but are not receiving them. The three major findings in this portion of the study, which will be discussed at length in this section, are:

1. ***The potential demand for support services greatly exceeds what is currently available.***
2. ***Service development is uneven throughout the province, creating regional disparities in service provision.***
3. ***The lack of adequate housing and other related community services compounds people's problems and actually reduces the impact of attendant care support for those who receive it.***

DEMAND EXCEEDS AVAILABLE SUPPORT SERVICES

It is clear from this Review that underfunding is the major reason for the limited quantity of support services. Services exist, but many people are unable to access them because most programs have more requests than they can handle.

> *"Announcements are made which makes it sound as if we are well taken care of and we're not. Programs are announced that services are available and they aren't really. False advertising makes the public unaware that there is a need. People are discouraged to help because government tells them all services are available." (Community Meeting)*
>
> *"The more people that know about Outreach, the more that want it. But the powers above become overwhelmed with the rapid growth and say 'hold on'." (Service Provider)*

There is also the strong perception that services for people with developmental handicaps take precedence over services for people with physical disabilities.

> *"It's irritating to hear that $600 million was spent last year for mental retardation and only $47 million to attendant care. There are maybe 250 spaces in Toronto for SSLU-there has to be more because that just isn't enough." (Consumers: SSLU)*

> *"We are concerned that we provide the only attendant care dollars; there should be access to dollars for case management; many people cannot access the support they need when they need it. Money and services in the disability area need to catch up to the mental retardation field." (MCSS staff)*

The differences between these two disability areas and the uneven policy development in the area of physical disability has been attributed by policy makers and consumer leaders to two factors:

- The advocacy movement in mental retardation has been focused and consistent in its beliefs since the late 1960s and early 1970s. The parent-directed movement has called for community living and normalization of opportunities for people with developmental disabilities. Until recently, there has been no equivalent, consistent advocacy on the part of people with physical disabilities.

- The notion of physical disabilities challenges our personal perceptions of vulnerability and as a result, our society tends to shy away from dealing with the issues. There is evidence, for example, that when one partner in a marriage becomes disabled the chances of separation are two to three times higher than the national average.

Determining the Demand from the Community

There are important demographic data from Canada which confirm that current support services in Ontario are very limited in the population they serve. The Report of the Canadian Health and Disability Survey conducted by Statistics Canada in 1983-84 provides the first systematic estimate of the level of dependence/independence of disabled persons in Canada. The survey data are limited because they do not include the needs of disabled people in institutions, nor do they include people's current services. Nevertheless, the survey provides a strong sense of unmet need.

The Report indicates that there are 937,000 adults with physical disabilities over the age of 15 in Ontario. Of this total, 39,000 people indicate they are dependent on others for "taking personal care of oneself," while 29,000 claim they are partially dependent on others for this function. In the area of "doing everyday work within the home, including cooking," 110,000 people report they are dependent, and 93,000 indicate they are partially dependent.

This Report of the Canadian Health and Disability Survey indicates that there are vast numbers of Ontario citizens who have support needs. In particular, the data strongly indicate the need for support services for older adults. The statistics point out that 35.5 percent of disabled adults are 65 years or older, and 59 percent are 55 years or older.

While there are very strong trends in the Report, it is much less easy to translate the data into specific support service needs. More concretely, we might ask if all 39,000 people who indicate they are dependent in the area of personal care require an attendant.

Even though Ministry SSLU and Outreach programs only serve about 1,034 (1986-87), we probably cannot assume that there are 37,000 other people in need of attendant care. First, it may be that other services such as the Integrated Homemaker Program (serving about 1,000 disabled and 10,000 elderly), Chronic Home Care, and private homemaking services may enable a percentage of the population to meet their needs adequately.

Second, it is not at all certain what other arrangements people make to meet their needs and we should not assume that need necessarily equates with service. While we do know there is tremendous burden and stress on some families, likely there are also situations where families are coping adequately with disability. Furthermore, staying with family may be a mutual preference for some people.

Despite these cautions, these figures are too powerful to be ignored. Even if we assume that only one third of the people who say they are dependent in two or more activities of daily living (including personal care) need attendant care, the total number of adults is still well over 10,000. Attendant care programs currently serve only 1,100 adults; therefore the need for additional funding of support services is obvious.

For planning purposes, the new Statistics Canada data to be released in the fall of 1988 will be even more helpful to MCSS. The *Health and Activity Limitation Survey* was carried out in 1986-87 as a supplement to the census. It will provide data on both community and institutional populations, and will include details on services received and reasons why assistance is not available.

Determining the Demand From People Currently in Institutions

Ministry figures show that there are 992 adults with physical disabilities living in chronic care institutions throughout the Province of Ontario. It is important to note that 95 percent of these individuals are under 65 years of age. Although the descriptive data on these people are not yet available, we know that many young physically disabled adults are in these settings. In one region that was visited, the regional chronic care institution currently is home to 26 adults with physical disabilities, most of whom are under 55 years of age. Our qualitative data in several places throughout this report show that many people want to be living in the community, and there is a strong fear of institutionalization.

Waiting Lists a Good Indication of Unmet Needs

The survey indicates that 38 percent of Outreach consumers and 41 percent of SSLU consumers feel that accessing support service programs requires a long wait for new people. A random selection of five Outreach programs in five separate regions confirms this consumer perception. The average number of people on Outreach waiting lists was 19 people per program. What we do not know is the number of people who can not even put their name on a waiting list because there are no Outreach programs in their area.

The situation creates a dilemma for service providers who must not only worry about the quality of service they are providing their clients but also must deal with long waiting lists.

> *"I have a conflict between quantity and quality. Some people have been receiving attendant care for 5 years and others have been on waiting lists for 2 years." (Service Provider: Community Meeting)*

"We can only provide for 8 clients ...there are 20 on the waiting list. There is at least a one year waiting list." (Service Provider: Outreach)

To understand what life is like for people on Outreach waiting lists, both quantitative and qualitative data were utilized. An initial analysis of the survey data provides us with some information on the ages and current living arrangements of 110 people. (See Tables 3 and 4).

Table 3

Ages of Consumers on Waiting List

ages	%
17-29	23
30-49	32.5
50-69	31
70 +	2.5

Although this table shows that the greatest proportion of people waiting for services are under 70 years of age, general demographic data indicate that the seniors' population is increasing and that we can expect to see a gradual increase in demand from seniors for support services.

Table 4

Current Living Arrangements of People on Outreach Waiting Lists

Current Living	%
by self	41
with parents	19
with relatives	32
with friends	3.8

These survey data provide us with some indication of how people are living, but they do not tell us about the personal concerns of people on the waiting list. The fact that so many people on waiting lists live alone, however, points out the vulnerability of many of these individuals. The story of one woman on the Outreach waiting list deeply exemplifies the lack of independence and control felt by most of the eighteen people who were interviewed.

Case Study

Ms. Smith is a mother of two pre-school age children. In July of 1987, she was hospitalized for corrective surgery related to her spina bifida. Her condition has subsequently deteriorated and she now needs attendant care from Outreach, which currently is not available. As a result she has been hospitalized unnecessarily for 8 months and separated from her family, except on weekends when her husband is home at least some of the time. Her husband is a waiter and does shift work, so Homemakers provides some child care in their home.

Not only is Ms. Smith very upset being separated from her young children, but Homemakers is threatening to withdraw child care, feeling that her children could go to day care. She feels she needs time with her children, particularly because of her absence from the home, so the last thing she wants is to be obliged to place them in day care.

"Right now I have absolutely no choices in my life...I have no control whatsoever. They say 'if you don't do it our way, then do it your way. Good luck.' My children already lack consistency - I'm trying to keep consistency in my life so when I go home, it can be consistent for them and me."

Other important supports in Ms. Smith's life, which ordinarily might get her through odd crises, have also been threatened. Her mother died last year and her best friend has just been hospitalized for cancer.

"I feel like I'm on my own, fighting for myself and my family."

Most other individuals on Outreach waiting lists emphasized the toll on marriages and relationships, the financial strain, and the stress on other family members and friends. People have been on waiting lists anywhere from six months to three years.

> *"My wife and I agreed that we had to separate my support needs from our relationship if the marriage was going to survive. So I had to hire a college student last year for $30,000 out of my own expense." (Consumer: Waiting List)*

Three people who are living alone also spoke of the isolation of the experience. Ultimately, as we have seen before, one of the greatest fears people have is that of being re-institutionalized.

> *"The problem is an urgent one. Unless financial answers are provided soon, I will be forced to make an alternate choice of lifestyle which will indeed be detrimental to my work as a writer and my life as a human being who has a right to dignity. I will be forced to go into a nursing home." (Consumer: Waiting List)*

> *"I gravely fear having to return to an institution because I can't afford to pay for my staff much longer." (Consumer: Waiting List)*

Regardless of the reason for having indequate support services, the effect is that undue stress is placed on the individual or family and friends, who either try to manage without support, or spend a lot of time, frustration, and personal expense finding alternatives. Our findings clearly indicate that lack of support services has serious consequences for people's sense of control over their lives.

> *"Your health has to break down before you can get attendant care for your spouse. I have been doing everything for my husband for 8 years and only now are we getting help. If I had been getting help all along, my health wouldn't have broken down." (Spouse: Consumer Outreach)*

> *"The problem is people on the waiting list; what the heck are they supposed to be doing in the meantime?... I get so fed up having to ask friends and relatives for things all the time." (Consumer: Waiting List)*

A detailed breakdown of the waiting list from one Outreach program in Table 5 illustrates what it would take to respond to these unmet needs. When reviewing this case study, of one particular program, the reader is cautioned not to assume these figures generalize across programs.

Table 5

Case Study

Detailed Breakdown of the Waiting List of One Outreach Program

People on waiting list	21
Range of disabilities	multiple sclerosis, muscular dystrophy, cerebral palsy, quadriplegia
People employed	2
Spouse provides a lot of support	9
Other family/friends provide support	6
Currently in SSLU	2
Receiving other attendant care	3
Receiving other home support ie Homemakers	13
Average # hrs./wk requested from Outreach (minimum)	13.6
Average projected annual cost/individual	$8 058
Total cost to respond to waiting list needs	$169 221

Administrative Overload

Most people agree that the administrative budget for Outreach, in particular, is far too low for these types of complex support programs. (MCSS staff; Service Providers).

> *"MCSS contracts out to agencies so that they don't have to pay high salaries and benefits. We are told to deliver extremely complex programs on little funding." (Consumer Leader)*
>
> *"When they were small, working out of the same office was O.K. but as it grew the phone lines got clogged, an attendant could never get through to say they couldn't come, or a client to complain or in an emergency. So we opened a separate office, with its own receptionist, own line to give a better response to clients... The administrative costs are too low to offer more flexibility. Things are so complex in this type of a program. It requires a lot of co-ordination for 25 people living separate independent lives. Home visits alone could consume most of the administration time they provide. So the issue is just not expanding to clients, but expanding administrative costs-they can't get good quality without it... And it would help so managers won't get worn out. " (Service Provider: Outreach)*

There is also a historical dimension to this issue of administrative overload. As some Ministry officials and service providers point out, when these programs were first set up, it was believed that administration and co-ordination would be fairly simple. Over time, a number of demands have increased the complexity of administration, including more paperwork, long waiting lists, additional staff to supervise, and more community planning and problem-solving. These dilemmas are particularly acute for the small agency and thus will be discussed further in Chapter 6 on "Models of Support Service."

Not only is there a concern about agency staff who are administering these attendant care projects, but also for MCSS staff in the Area Offices. Typically, Ministry program supervisors have 15-30 programs to supervise.

REGIONAL DISPARITIES EXIST

The data show that there are many positive aspects of receiving service in rural areas, such as the increased flexibility of services to respond to the individualized needs of people, as well as the stronger sense of community. (MCSS staff). In general, for example, Outreach is seen as a viable way of providing attendant care service to people in rural areas.

> *"I would like to develop a rural networking approach... people living a small town life with small town people taking care of them." (Service Provider)*
>
> *"In many cases, the families help us locate people. Especially in outlying areas, it's important to find the right people." (Service Provider: Outreach)*
>
> *"We are trying to get services to people rather than the other way around. In rural areas, we do a modified brokerage system. People do their own hiring, although we have expertise in training." (Service Provider)*

Despite these positive features, there has been uneven service development throughout the province, resulting in regional disparities and a variety of unmet consumer needs. One of the contributing factors is that SSLU projects are found only in urban areas.

> *"Smaller communities have very limited support. Maybe because they don't meet the Ministry guidelines, (a minimum of ten people in SSLU units) or resources aren't in the town because of isolation or there are only 2-3 people who need support care in the whole community. So people end up moving to Thunder Bay or surviving with limited support ie. Homecare or depending on family." (Community Meeting)*
>
> *"As a provincial organization, we can see the differences between programs in the North and in the South. In the North, people need to make do." (Consumer Leader)*

This regional disparity is further complicated by the lack of other essential support services, such as transportation. People in rural areas are left with the overall sense that services in rural areas are neglected and lacking.

> *"In rural areas, transportation is a problem. It is difficult for a person with a disability to get around and it may be difficult for attendants to get to them." (Community Meeting)*

> *"There's nothing at all for people outside of the city limits. They can't get in for appointments, therapy or anything." (Community Meeting)*

> *"Because you choose to live in the country, you choose not to get available help says my vocational rehabilitation counselor. I don't see why I would have to move to the city which I hate, just so that I can get transportation." (Consumer: Waiting List)*

Regional disparities and limited rural services often require individuals to leave their community to access services in a bigger community (Consumer Leaders; Consumers: SSLU), since there are often no funds to support just one or two people. (Consumer Leaders)

> *"You have to move from your home into the city before you can qualify for help. We were living for 15 years in the country and we had to move to the city to qualify." (Consumer: Outreach)*

> *"We lived in the North and had to sell our house and move here because we could no longer afford to pay for homemaking staff...(I) had to be institutionalized... We have a four year old who has seen his mom very little." (Consumer: Outreach)*

Regional disparities can obviously have a tremendous negative impact on the person's lifestyle and relationships with family and friends. (Consumers: SSLU). Further discussions of impact of moving away from families can be found in Chapter 7 on "Restrictive Policies."

> *"I had to move from Toronto to here to get an apartment but I only knew one person in Hamilton so it was quite lonely for a long time." (Consumer: SSLU)*

> *"I had to be separated from my husband. I moved into an SSLU Co-op project, but my husband remained on the farm to work." (Consumer: SSLU)*

LIMITED COMMUNITY SERVICES

A lack of essential community backup supports exists not only in rural areas, but in urban centres as well. While individuals may be receiving personal supports through SSLU or Outreach, they may continue to be isolated due to lack of appropriate housing or poor transportation, and limited day programs and employment opportunities. This "crisis" of limited community services is particularly difficult for individuals who are not receiving SSLU or Outreach supports.

Housing

Housing is unquestionably the community resource that people feel is most lacking. The housing shortage in general is seriously affecting many disabled people, particularly those who require both accessible and affordable housing. This problem is seen as going hand in hand with support service issues. (Consumer Leaders; Service Providers: SSLU & Outreach; MCSS staff; Consumers: SSLU and Outreach)

> *"When you're living at home, they feel you have suitable housing. They feel you can stay there as long as you want." (Consumer: SSLU)*

> *"It is particularly acute for people who are just coming out of rehabilitation settings - once you're in there (rehab setting) your chances of getting out are so slim. They figure you've got a place to live." (Consumer Leader)*

In many communities, the vacancy rate in rental accommodation is close to 0 percent. Besides this low vacancy rate, most new housing is not being made accessible or even well designed, due to lack of incentives for builders and the lack of awareness on the part of builders. (Community Meetings; Consumers: Outreach)

> *"There are no incentives for builders to make accessible places except if they are 'converting to rent'. We could have guaranteed long term leases with regular apartments. If there was a high vacancy rate, then the motivation would be there, so we need financial incentives, unless of course builders could be socially conscious." (Service Provider)*

> *"There is a need for increased availability of integrated accessible housing built into the community. It should be barrier-free. Housing is important because you can't be totally integrated into the community unless you can live independently in it." (Community Meeting)*

There is a strong feeling that various Ministries do not cooperate around supportive housing. (Consumers; Community Meeting; Service Providers)

> *"The Ministry of Housing needs to meet with MCSS and sort out their responsibilities with regards to tenants. There is no money for subsidized housing. The housing regulations are so complicated. There needs to be more simplification of this program." (Consumer: Outreach)*

Next to lack of housing, inadequate public transportation and the need for employment and day programs are large concerns for people who need support and want to live more independently.

SUMMARY AND RECOMMENDATIONS

This Chapter has presented a number of key findings which have important policy implications. First, data from several sources demonstrate the need for additional funding to respond to the large number of people needing support who are currently not receiving service. The demographic data presents a somewhat overwhelming picture of people's perception of need. Even taking very conservative figures, it is clear that the number of people who need attendant care exceeds the level of current service by three to ten times.

The data from people on Outreach waiting lists are in some ways the most convincing evidence that additional service is required as soon as possible. The stories from these individuals are painful and compelling. The burden on families is extensive, and many people feel they lack independence and control because they do not receive support service.

Based upon this clear need for additional support services, it is recommended:

7. **That the Ministry of Community and Social Services significantly increase the amount of support services and expand its programs for attendant care and independent living assistance for people with physical disabilities not yet receiving any service, and**

8. **That the Ministry phase in new monies for individualized support services as part of a long range comprehensive plan to address the needs of people with physical disabilities in Ontario.**

Second, many of the one thousand people with physical disabilities living in chronic care institutions should have an opportunity to live in the community with support. At some community meetings, families expressed that they wanted a family member moved to the community. It has already been noted in the "Needs" chapter that fear of institutionalization is one of the most compelling motivations for people who want more independence and control in their lives. In a study done in Hamilton that included people from institutions, about one-third of the individuals with physical disabilities indicated they would prefer to live in the community (Hamilton Social Planning and Research Council, 1986). There is reason to suspect that this figure would be considerably higher once people knew that the support they required would be available. Recent studies have shown that when people have experienced community living for their family member, they usually reverse earlier negative attitudes toward deinstitutionalization (Conroy & Bradley, 1985; Lord & Hearn, 1987).

The Ministries of Health and Community and Social Services in Ontario have already shown leadership with their plan to move about 1,000 people with developmental handicaps from Homes for Special Care and nursing homes to the community.

A similar plan should now be considered for people with physical disabilities. Not only must this plan address the issue of bringing out people who are currently institutionalized, but it must also guarantee that these vacancies will not be filled by the inappropriate placement of other physically disabled individuals. This is the only thing that can permanently alleviate the ongoing fears that almost every individual and their family has about being institutionalized in the future. Evidence from other jurisdictions has shown that if a deinstitutionalization plan does not specifically deal with this issue of "zero entrance", then institutions become a revolving door for both former and newly disabled people (McWhorter & Kappel, 1984). It is therefore recommended:

9. **That the government commission a study to be done with physically disabled people in institutions, chronic care facilities, and nursing homes to determine the exact number of people who are in need of having the opportunity to move to the community; and that this study include an analysis of the support which would be required, and the framework for the deinstitutionalization plan.**

10. **That the Ministry of Community and Social Services cooperate with the Ministry of Health in developing a plan to move people identified in a study out of chronic care institutions and nursing homes over the next five years; and that the plan include a commitment to "zero entrance" of inappropriately placed physically disabled adults into such facilities.**

Third, uneven service development has resulted in regional disparities which have had particularly negative consequences on consumers in isolated, rural areas. This serious dilemma has important policy implications.

Many consumers, consumer leaders, and MCSS program supervisors emphasize that people should not have to move to a new locality in order to receive the services they need. Furthermore, a more formal program delivery approach may not be appropriate for such individuals. Program options need to be available so that the consumer can either access an existing Outreach program or be given the funds to acquire their own support.

Based on the data and the above analysis, it is recommended:

11. **That the catchment areas of existing Outreach programs be enlarged, and/or new programs be added, to ensure that individuals have the choice to access the nearest Outreach program.**

12. **That consumers be given the option of either obtaining service from Outreach or receiving individual funding directly from the Ministry to purchase and manage their own service.**

This recommendation will be discussed in depth in Chapter 10.

Fourth, accessible affordable housing is a critical community resource that is inextricably linked to support services. Unfortunately, accessible housing that is properly designed, reasonably located, and affordably priced, is in short supply. There is a need for a more generic approach to building code standards in order to ensure that a number of units in all new buildings are accessible. These standards will have to be enforced at the municipal level. Therefore, it is recommended:

13. That the Ministry seek more support from the Ministry of Housing to expand the number of accessible, affordable housing units in the province and to ensure that municipalities enforce building code standards.

Chapter 6

AN ANALYSIS OF MODELS OF SUPPORT SERVICE

This Chapter begins with a description of the different models of support service living units; this is followed by an analysis of the various SSLU models in light of the findings from this data. The same procedure is then used for the discussion of the Outreach program.

SUPPORT SERVICE LIVING UNITS: FIVE MAIN MODELS OF SERVICE DELIVERY

The data from observations and interviews show that there is wide variation in service delivery of SSLU projects. The projects divide into five predominant models. The first four models are directly linked to types of housing. The fifth model is a transitional service which can be provided in any of the four housing models. These models are described below.

A. Larger Residential Settings

Two larger residential settings were visited during the Review. Although one of these residential facilities is funded under the "Homes for Retarded Persons Act" and the other is funded under the more recent "Ministry and Social Services Act," both facilities share the same general characteristics.

One of these settings is situated on the outskirts of a large metropolitan area, isolated from any residential community or neighbourhood. The second setting is located in an urban area, surrounded by other institutional type facilities, but close to the downtown area.

This model of support service is characterized by a number of features.

- Residents live in a building large enough to hold 20-40 people with physical disabilities. One of the projects houses 34 people, the other one 29 people.

- The building is segregated somewhat from the community either in appearance or reality.

- Staff support is provided in a number of areas, including attendant care, life skills, and housekeeping. Generally, residents go to a dining room for their meals, and may also be involved in day programs in the same setting.

- Some of the residents in these sites have developmental handicaps, and generally residents are more likely to have a dual or multiple disability than residents in other models.

- A significant number of the residents of these settings have a need for high levels of support.

- Twenty-four hour support is available in all of these large residential settings. An example of the hours of support provided in one of these settings is outlined in Table 6.

Table 6

Support Service Received in Large Residential Setting

Hours/Day	% of residents
2-4	16
4-6	61
6-8	20

B. Group Homes

The group home model of support is not a common form of service delivery for people with physical disabilities. More typically, the group home has become the predominant model for people with developmental handicaps. During this Review, two group homes were examined, one of which houses five, and the other seven, people with physical disabilities. We also gained insights into a small number of other group homes, from people at community meetings.

This model of support service is characterized by a number of features.

- The group home model implies "group living," but it generally differs from a co-operative model, where residents have control over the management of the home. In these homes staff clearly are in charge.
- The group homes have a somewhat "family atmosphere," and the role of support staff is to primarily support residents with their physical needs. This includes help with personal care as well as with household tasks and maintenance.
- Twenty-four hour support is available. An example of the hours of support provided in one home is outlined in Table 7.

Table 7

Support Service Received in Group Home

Hours/Day	% of residents
1-2	41
3-4	40
5-6	19

- The group home also serves as a "transitional" setting. The assumption is that the security and support of group living can be a positive transition to more independent living.

C. Segregated Apartment

The segregated apartment model of support is found in a few locations in Ontario. In this model, an entire apartment block houses people with physical disabilities and their families. This Review examined two segregated apartments in two separate cities, one which had 14 units and another which had 16 units. Both of these apartment blocks were in busy urban areas close to shopping and transportation.

This model of support service is characterized by a number of features.

- Each individual or family has their own apartment. Attendant care support is provided, but individual residents and families are responsible for their other living needs, such as planning their meals, budgeting, and paying for their rent.

- The support needs vary among the residents, as indicated by the breakdown of hours people receive shown in Table 8, which represents one of the segregated apartments.

Table 8

Support Service Received in Segregated Apartment

Hours/Day	% of residents
1-2	58
3-4	19
5+	22

In other words, most of these settings are structured to accommodate a combination of people with of low, medium, and high support needs.

- The segregated apartment block model also seems to be a model which is utilized for "transitional living." As with the group home model, the expectation is that the security and support provided in such a setting will promote a positive transition to more independent living.

D. Integrated/Dispersed Apartment

The integrated/dispersed apartment has become the most common model for delivery of Support Service Living Units. Four of these projects were examined during this Review. All of these projects are within urban areas, relatively close to shopping and transportation. They are characterized by a number of common features.

- Each project serves approximately twelve to fourteen individuals with a minumum of 10 units. One or two bedroom apartments are generally dispersed throughout a large rental apartment complex or housing co-operative. Smaller apartment buildings have a total of 30 to 40 units, while the larger buildings have anywhere from 160 to 200 units.

- Like the segregated apartments, the agency which provides support service generally has an office in the apartment building or townhouse complex, with 24-hour support and attendants on duty. Attendant care support is generally provided up to 4-5 hours a day on a pre-scheduled and "on-call basis."

- Several of the buildings which house integrated/dispersed units are designed to serve other minority groups. In two sites, for example, elderly people reside in approximately 50 percent of the units, while in another project about 50 percent of the residents are low income people.

- Life skills training is generally not part of this support model. However, in one project a part-time life skills co-ordinator has been hired with outside funding and is available to assist residents with a number of tasks, including banking, menu planning, etc.

- Like the segregated apartment model, people living in integrated apartments represent a range of disabled people. Most of the projects continue to base their model on the assumption that one-third of the residents will require light support, one-third will require heavy support and the final one-third will require medium support. This differentiation was initially designed to accommodate flexible staffing and 24-hour "on call" support.

E. Transitional Living Models

As part of the movement towards assisting people with disabilities to achieve the highest possible level of independence and community integration, transitional programs have emerged as a stepping stone for people who are newly injured, or who have spent a significant portion of their lives in institutions or in protective family settings. Four SSLU projects with a transitional living component were visited during the Review.

The initiative for this form of program seems to have arisen from local communities. To date, there are no MCSS provincial guidelines for transitional programs. Instead, transitional models have emerged as a local response to consumer needs, and perhaps as a response to the needs of service providers who are dealing with a high volume of consumer turnover in their projects.

This particular model of support service has some of the following features.

- The setting of the transitional programs can vary from being in a relatively large, segregated project devoted entirely to transitional living; to group homes; to having a few units designated as transitional living within an integrated SSLU project. The common element to all of these settings is that the *housing is temporary*.

- In most cases the tenants are expected to participate in setting their own goals and objectives for training. The person may sign a contract outlining the goals to be achieved and the time frame.

- Life skills training is designed to assist people to develop their capabilities in the following areas of daily living - personal care, nutrition, housekeeping, money management, mobility and transportation.

- Individuals are expected to be actively involved in a community activity - voluntary, educational or vocational. The emphasis in some programs is on enabling people to become more self-sufficient and better integrated within the community.

- The average length of stay is supposed to be 12-18 months. The transitional programs say they assist the individual to move into a permanent home. The housing shortage makes this task very difficult, so that in reality the length of stay varies considerably among individuals and projects.

AN ANALYSIS OF SSLU MODELS

In analyzing the various support service models, an attempt was made to gain a broad sense of how service structures might vary site by site. At a program level, the specific features of each of the models were compared. To provide a framework for the analysis, people's core needs were utilized, as was the predominant theme of independence and control.

It seems clear that the manner in which services are structured has been influenced by the changing trends in awareness about the concepts of independent living, and by the philosophical orientation of the specific service provider. Furthermore, services are influenced by the constraints in current policies that limit the ability to respond flexibly to individual needs.

Within the various SSLU models, there are definite links between the organizational model of service delivery, and the type of housing in which the support is provided. This seems to be particularly true for some of the earlier models of support, such as some of the original Participation Houses.

The four major findings that emerge from our analysis of the data on models are:

1. ***The organizational structure of a particular model of service delivery is dependent upon the philosophical orientation of the sponsoring group and the community leadership.***

2. ***The tight links between the form of housing and the method of support service delivery creates the perception of a continuum of services rather than an array of independent living options.***

3. ***Consumer involvement and control at a personal level and in agency decision-making is not a strong feature in most projects.***

4. ***The goal of independent living and community integration are not always successfully achieved by the different models.***

Factors Influencing the Approach to Support Services

Wide variations exist among the different support service models. These variations are reflective of i) the strength of a consumer base in a specific community; ii) the already existing service structure; and iii) the interpretation of Ministry SSLU guidelines at the MCSS Area Office level.

In four of the communities, a virtual monopoly exists for the SSLU and Outreach programs. In two of these sites, where the organizations have either a strong consumer base or are completely consumer controlled, the service monopoly does not seem to pose a problem. A few consumers comment that it is difficult to criticize the only game in town, but they also acknowledge that the opportunities exist for them to become involved in the organizational decision-making.

In the other two sites where monopolies exist, the support programs have been initiated and implemented by service providers. The consumers in one community are very angry and resentful of their limited options. They seem to have no input into how the services are designed or operated, and also have no choice but to go through a rigid system of programs.

Obviously, the amount of variation between different communities, in terms of who offers the programs and how the programs are structured, raises questions about how decisions are being made at the local level. For example, some MCSS Area Offices seem to do little systematic assessment of whether or not service providers are in fact promoting integration and independence in the community.

Housing and Services - A Continuum?

The five models of support service - larger residential settings, group homes, transitional programs, segregated apartments, and integrated apartments - offer a spectrum of options ranging from the more protective segregated environment to the integrated setting where theoretically one should experience the greatest opportunity for community integration. The danger with linking the form of housing so closely to the manner in which services are provided, lies in the fact that support programs are seen as a continuum of service delivery as opposed to being an array of choices for independent living.

A continuum tends to lock the consumer into rigid step-by-step service structures that range from the most to the least segregated. In the two larger residential settings, for example, the assumption is that only people with limited or moderate support needs can move to more independent options. This notion that the support one needs *should* be tied to a certain type of housing limits consumer options and the choices people want to make about their lifestyle.

Some of the program models have a greater potential than others to feed into this concept of a service continuum; the transitional program is a prime example. Because the transitional programs are tied to a temporary form of housing (be it group homes, segregated settings or integrated apartments) rather than to the individual, there is a concern that people can be slotted into transitional programs as an unavoidable step along the road to permanent housing and community integration.

In this Review, our intent is to sound a cautionary note. As Charles Galloway, in his critique of the continuum, writes:

> Once located along the service continuum, one will be required to "learn" his or her way out of that point and into the next, less segregative, facility or program. (You will hear increasing discussion of behavioral "exit criteria" for movement along the continuum.) Finally, one's prognosis for full participation as valued members of the community will be determined by his or her present location along the service continuum (Galloway, 1981, p.4).

One of the sites that we visited seems to epitomize all that is negative with the continuum framework. The project is presented below as a short case study:

Case Study

> People who are admitted to this particular project pass through a series of life skills training and assessments, to progressively higher levels of

independence. Consumers who enter at level 1 and successfully acquire the necessary skills for daily living, are encouraged to move to a second SSLU apartment, level 2, where there is less supervision. The eventual expectation is that higher functioning disabled people should be looking for community housing.

The comments of consumers and service providers suggest that people within this particular transitional setting are expected to adapt to a rigid schedule of life skills programs and assessments, with very little opportunity to pursue individual interests. The remark of one senior program manager captures the apparent orientation of this project.

"It's like a mini-group home. These people need structure and a consistent staff group. They also have to learn that independence does not mean doing what I want, when I want." (Senior Program Manager)

From the perspective of the consumers who were interviewed, the result is a highly structured enviroment that appears to rely heavily on behaviour modification techniques.

"You have to make a list for grocery shopping. You are not allowed to deviate at all. If you put something in your basket that wasn't on the list, they (attendants) just put it back on the shelf. How do people know one month in advance what they want to eat for dinner? You have to eat what is on the meal plan or not at all, or you get reported (to the key worker)."

"I was once out of town and I was told that they couldn't put me to bed because I forgot to book. Since I forgot to book (even though I returned at 2:00 pm), I had to ask my parents (age 75) to put me to bed."

Consumers in this project seem to be particularly concerned about the lack of control that they experience in all aspects of their lives, including limited support for more community integration. The ongoing assessment process is perceived to contribute to this lack of control.

"Your workers are supposed to be helpful but they can get in your way (of progress). Suppose you want to move out and they

don't want you to, then when assessment time comes you are told that you aren't ready."

Consumer Involvement and Control

In Chapter 3, the different levels of independence and control were presented. In the analysis of these various support models, these levels were studied in terms of the degree to which the programs support people in directing their own care and, as an out flow of that level of control, whether consumers actively participate in the decision-making of agencies sponsoring the projects.

Supporting consumers to direct their own care is the professed philosophy of most of the settings that we visited. However, some of the models clearly were not structured in a way to achieve this goal. For example, perceptions of residents and staff confirm our observations that consumers in the two larger residential sites generally do not direct their own support. Although the assumption is made by some people that this model is designed to serve people with high needs who cannot direct their own care, the researchers' observations suggest that many consumers could direct their own care if supported to do so. The philosophical orientation of the two larger residential settings does not appear to allow for consumers to be involved in the decision-making process in any significant way. People are expected to co-operate with staff and attend programs that have been designed without their input, to eat at set hours in the cafeteria, and to have little control over their daily regime.

With group homes, as in the previous model, there is evidence of only a token amount of support for consumers to direct their own care or participate in the decision-making of the agency which runs the home. Unlike the larger group residence, the small group home model should not contradict the notion of consumer direction and participation. However, experience in this Review and in other studies (Lord & Hearn, 1987), is that group home agencies, like the larger residential settings, tend to think of the group home as a congregation of people, not individuals. Consequently, the potential for consumer control is very limited.

In the segregated apartments, we observed that staff clearly have a dominant role to play in the delivery of the support services. Consumers may be encouraged to direct their own supports, but in reality this capacity is limited by staff schedules and agency philosophies. In some settings, consumer participation in decision-making has increased in recent years, although even in these settings, participation continues to be limited.

The degree to which consumers are encouraged and supported to direct their own care is somewhat difficult to determine in dispersed apartments. Our sense is that much of the process is "negotiated" between the consumer and the agency staff. Ultimately, the problems associated with staff attitudes and scheduling seem to be common to all projects.

In terms of consumer representation in the operation and decision-making process, most integrated/dispersed projects are similar to the other SSLU models - the organizational model of the projects keeps consumer participation to a minumum.

Our data show that people are interested in having more input into the organizational decision making.

> *"All new projects should have lots of consumers on their boards - otherwise things aren't realistic and it won't work out. Usually the structure of these organizations is an executive director at the top, mangers next, attendants with a head attendant, and then consumers at the bottom. That's not right. That's how to run it like a mini institution." (Community Meeting)*

> *"It's important that strong consumer control be built in from the beginning - it would not have happened here if it weren't for being on the board. The others never would have thought of it themselves, but when he raised it, they were responsive." (Service Provider: Outreach)*

On the other hand, the experience of some people (Consumer Leaders; Consumers: SSLU) indicates that there is little real involvement of the consumers in certain agencies and boards that provide support services. The two quotes below highlight the frustration people feel when they sit on boards and have very little impact on service delivery decisions.

> *"I'm on two committees and thinking of quitting. There's no action. It needs to be formalized - not a time for social chit chat." (Consumer)*

> *"One person is a tenant rep and on the Board of Directors. It's a token position...they don't allow him to vote on matters. He was*

asked to leave the board because he voiced opinions. He doesn't have any say in hiring." (Consumer Leader)

A few consumer leaders strongly recommend structural changes in SSLUs which would significantly increase tenant control in these projects.

Support service projects which have been consumer initiated are the ones that demonstrate the strongest commitment to consumer control in decision making. A few of the projects and organizations that were visited as part of this Review had built in good consumer representation on the boards and committees. A case study of one of these projects is presented below.

Case Study

Nucleus House in Toronto is a unique SSLU project because it was initiated jointly by a board of consumers and attendants. Its governing structure requires that the project be run by a majority of consumers; six of the eleven board members of the project are tenants of the building. The project is housed within a fifteen story highrise with one unit on each floor belonging to a person with a disability. With a five year history, it appears that there are several lessons from the Nucleus House experience.

- Consumers can be an intricate part of the organization and the decision-making of an SSLU project.

- A fair degree of support may be needed during the development of the project. Nucleus House used a broad based advisory committee and worked closely with a voluntary organization which contributed expertise and support.

- A consumer directed project, like all others, needs a few key people to provide leadership and vision.

- Staff need to learn that they are responsible to the consumer, and consumers need to support each other in effectively directing their support care and in participating in the project.

- Consumer direction and participation does not eliminate difficulties in service implementation, but it does ensure that the project's philosophy and practice more closely reflect the consumers' needs and wishes.

Independent Living and Community Integration

People who have left large institutions or their parents' homes are generally appreciative of the opportunity to live more independently, regardless of the support service model. There is also widespread satisfaction with the security that each model offers. People know that support is available around the clock, for emergencies or for unexpected needs. Finally, some people appreciate the fact that they are not living in an isolated setting, but have opportunities for contact and friendship within their project.

Despite these indicators of consumer satisfaction, each model has limitations in its ability to promote independent living and community integration.

Several residents and some service providers indicate that the large residential settings significantly limit people's capacity for independent living. Others express concern that the model is too segregated and institutional. The large numbers of people associated with the setting limits the assimilation of the service or the people into the surrounding neighbourhood. The Ontario Advisory Council for Disabled Persons, in its discussion paper on *Independent Living-the Time is Now* (1988), argues that SSLU projects should no longer be of such a size that they can become mini-institutions.

Group homes may or may not be part of the neighbourhood and the degree to which residents are integrated within the community seems to depend upon the initiation of residents and staff. Based on previous research (Lord & Hearn, 1987), it has been noted that community integration is not a natural consequence for people living in group homes. A well thought out, pro-active process is essential for the achievement of community integration.

Transitional models of support service state that community integration is one of the criterion for entering the program. People must be involved in a volunteer, vocational, or educational activity. Once again, it is difficult to assess how well this is accomplished. If someone leaves the transitional setting to spend their day in a sheltered workshop, that is an extremely limited view of community integration. On the other hand, a well-run transitional centre supports people in becoming knowledgeable about their community and its resources.

Both the perception and reality of segregated apartments seems to be that they are somewhat isolated from the community. People do not have non-disabled neighbours and if they want to interact with non-disabled people other than staff, they must venture into the community. Some consumers express concerns about their isolation from the community.

Residents in integrated dispersed models have ready access to the community, and a great deal of potential for integration with non-disabled people. This was mentioned by several people. However, there is also concern that the potential for integration is limited in a building which houses primarily one other group of citizens - such as elderly people. Furthermore, if the building is not located near an accessible shopping area, this will have an impact on a person's ability to function independently and to become familiar with their community. As with all the projects, transportation constraints can severely curtail an individual's community activities.

OUTREACH MODELS

Who Provides the Service

There are no clear guidelines for MCSS program staff regarding how to "match" the demands of the program with an appropriate service provider. Thus, wide variations exist in who delivers the Outreach program. In assessing Outreach programs, it was noted that:

- Most agencies which provide the service, such as Cheshire Homes or March of Dimes, specifically serve disabled people.

- A small number of agencies have traditionally served other groups, such as the elderly, or are generic services such as Homemakers or Red Cross.

- Several Outreach programs are part of the same agency that provides SSLU in that community.

- Two or three Outreach programs purchase service from another agency such as Red Cross.

How the Service is Provided

- Most of the agencies reviewed try to accommodate consumers by offering up to three hours of care in *flexible* blocks throughout the day.

- Some agencies carefully match an attendant for the individual; encourage that person to hire their own attendant; and support that attendant so that the individual only requires one attendant. Other agencies provide the consumer with whichever attendant is on duty.

- Most Outreach agencies hire part-time attendants and pay them an hourly wage for shift work. A few agencies hire some full-time attendants (which benefits the employee), but have indicated that in order to do this, flexibility is lost for the consumer.

- Most Outreach agencies develop a pool of attendants which they draw upon from a certain geographical area. One service provider looks for attendants in the neighbourhood of the consumer to minimize travel and maximize reliability.

These wide variations in implementation result in a variety of consumer outcomes. In Chapter 7, the Outreach guidelines are examined to suggest ways to ensure somewhat more predictable consumer outcomes from this program.

Role of the Consumer

- In a minority of the Outreach agencies, consumers are encouraged to hire, train, monitor, and supervise their own attendants. One program in particular involves consumers, from day one, in the planning of the program delivery. With consumer input, the program has evolved into a form of brokerage, to be discussed further in Chapter 10.

- In the remaining agencies, the staff organize all of the attendant care and the consumer does not play a role.

- There appear to be differences between rural and urban dimensions of Outreach, even within the same agency. Rural consumers more often are able to find and supervise their own attendants. Agencies admit this increased consumer control occurs because agencies do not have the manpower to closely supervise consumers and attendants in far away rural areas.

An Analysis of Outreach Programs

People are quite pleased with the Outreach program, despite the fact that there was a frequently expressed wish for more hours. Of the individuals surveyed, 76 percent believe that the program "encourages consumers to direct their support workers." An even larger 92 percent indicate that their attendant is "willing to do tasks most essential to me". On the one hand, these figures speak well for the ability of consumers to direct their own care within the Outreach program. On the other hand, consumers in personal interviews indicated that they were reluctant to speak negatively about a program that they were so dependent on.

The data from this Review complement an earlier evaluation of the Outreach program, conducted in 1986 by the Ministry of Community and Social Services. In that evaluation, 86 percent of the respondents were happy with the quality of service, and approximately 76 percent claimed that the Outreach program was "good" or "very good."

Although the Outreach program appears to promote community integration because it is offered in people's homes, the fact that attendants do not routinely escort their clients to do shopping, banking or community activities, means that some people lead very isolated lives. In the cases where people can resume their normal working lives as a result of Outreach in the home, integration is obviously achieved. However, for people with higher support needs, their chances for community integration often remain relatively slim.

With respect to consumer involvement in service delivery decision-making, there are some excellent models where consumer involvement is a working reality. Because these examples are not the norm, attention needs to be given to how to encourage other Outreach and SSLU projects to involve consumers in a more systematic fashion.

SUMMARY AND RECOMMENDATIONS

This chapter on models of support service has highlighted a number of important findings which have significant policy implications.

First, consumers within all service models seem relatively satisfied with their current situation, particularly with the feelings of security. At the same time, there is the recognition that more could be done to promote individual control at a personal level and at a decision-making level. Policy options must recognize the paradox in this analysis; that is, the strong need many consumers have for security and for 24-hour "on call" support, while recognizing the equally strong desire consumers have for more independence and control.

Second, although there are concerns and limitations raised about all models, the majority of criticisms pertain to the segregated models. There is a clear sense from the data that disabled people want more community involvment and participation. Most service providers also emphasized these values.

Policy options must reflect this current trend toward independence and community living in the physical disability area as well as within other jurisdictions. It is noteworthy that service initiatives for elderly people are increasingly promoting home support and independent living (National Advisory Council on Aging, 1987). The area of developmental disabilities has often demonstrated the most comprehensive approach to community integration. John O'Brien (1985), for example, has developed a "Framework for Accomplishments" for people with developmental handicaps which defines five achievements for community and independent living. These accomplishments include community presence, participation, status, competence, and autonomy. In mental health, policy and advocacy efforts with people labelled mentally ill have increasingly focused on these areas. For example, the "Framework for Support" project of the Canadian Mental Health Association emphasizes community integration and participation as central to the notion that people with mental health problems can participate in their communities with support (Church & Trainer, 1984).

Based on the Review data and the foregoing analysis, it is recommended:

14. That all future SSLU projects be developed on principles of community integration, to ensure that the project location, size, housing type, and function of the support services be designed to maximize independent living and community participation.

Third, our analysis of models shows how support services are intricately linked with housing. A recently completed study commissioned by the Ontario Office for Disabled Persons (Abt Associates, 1988), outlines a number of housing classification systems, all of which combine housing type with support service needs. For example, a typical classification might propose independent, semi-independent, transitional facilities, and dependent housing.

Our findings suggest that policy options must reflect a re-thinking of these narrow "step" or "continuum" classification schemes. Consumer leaders in several communities were particularly concerned about the relationship between housing and the provision of support services. They emphasize that future support service policy needs to separate or "de-link" housing from support service provision. In other words, because someone needs five hours per day of support or "on call" twenty-four hour support should not require that the person live in a segregated SSLU project.

Based on the Review data and the above analysis, it is recommended:

15. **That future support service policy be tied to the individual rather than to housing models; and that an array of individualized support services that are not based upon a continuum be developed to maximize consumer choice.**

16. **That current and future SSLU projects be encouraged to develop innovative approaches to support services which would include clustering of people in neighbourhoods, not just in a single building.**

17. **That the Ministry promote individualized transitional services for people in their permanent community homes; that the Ministry commission a study to design the most effective way to develop and deliver such individualized transitional services; and that the study examine the role of independent living centres as a vehicle for providing these services.**

Fourth, it is clear from the Review that service agencies providing SSLU or Outreach have a variety of standards in regard to "promoting self-directed care" and in relation to "consumer participation in the organization and decision-making of projects." Many agencies are struggling with how to implement concepts related to independent living and consumer participation. The fact that there is such a wide variation among agencies also suggests that more structured support should be given to service providers and the organizations' boards. There is a precedent for this approach. The Ministry's Multi-Year Plan for people with developmental disabilities has designated funds and resources to assist agencies who are developing services and programs.

Policy options must reflect the growing thrust of independent living and consumer participation (Derkson, 1986; De Jong, 1979; Hutchison et. al., 1985). The data suggest that consumer direction and participation "grounds" a project in very important ways; the voice of the consumer is heard and decision-makers become cognizant of the need to reflect upon real consumer concerns and issues. In fact, the individualized, self-directed nature of personal support services lend themselves to high degrees of consumer direction and control.

Based upon this analysis and the Review data, it is recommended:

18. That the Ministry develop clear guidelines to assist MCSS Area Offices in determining which organizations are most appropriate to provide future Outreach and SSLU programs in a manner that fulfills the goals of independent living and consumer participation.

19. That a high degree of consumer participation be mandated for new SSLU and Outreach agencies; and that current projects be required to phase-in plans of how they will increase consumer participation in their agency structure over the next two years.

20. That the Ministry develop a resource team whose mandate would be to assist agencies in developing their capacity to deliver coherent, consumer-oriented services, while respecting local decision-making and initiatives.

Chapter 7

RESTRICTIVE POLICIES OF SUPPORT SERVICE PROGRAMS

It is clear from all sources that both individual consumers and service providers are experiencing a great deal of difficulty because of restrictive policies surrounding the Outreach and SSLU programs.

> *"The program parameters need to be changed to allow greater flexibility. Right now we have to justify how we're orchestrating the services around the individual." (Consumer: Outreach)*
>
> *"Even though attendant care is a good idea, I will need to see if it's more trouble than it's worth. It's just one more thing to add to the already existing chaos. Some services cause more restrictions in your life than they're worth." (Consumer)*
>
> *"Why can't we get support workers the same way we get a babysitter. The forms required for support care mean you have to prove yourself every time you want to satisfy a need. People won't go through the hoops."(Consumer Leader)*

An in-depth analysis reveals that some of these difficulties are due to MCSS policies, others result from local interpretations, and still others are due to in-house agency policies. In this Chapter, we will try, wherever possible, to point out whether the problem is seen as being with the Ministry policy or with local interpretation of policies.

The broad array of concerns around policies can be broken down into two simple categories:

1. ***Policies and practices which make it difficult for individuals to be eligible for services.***

2. ***Policies and practices which make it difficult for individuals to have their needs met once they are receiving service.***

Each of these two major categories will be discussed in this Chapter. As well, alternative strategies that people suggest or have tried will be shared.

RESTRICTIVE POLICIES MAKE IT HARD TO BE ELIGIBLE FOR SUPPORT SERVICES

Many people are unable to get Outreach and SSLU support services at all because of restrictive guidelines in areas such as the requirement that the consumer have a back-up system, that consumers be able to "direct their own care," and family status. Other people are delayed in getting the service because of lack of co-ordination around policies and housing.

> *"I was in the hospital, but couldn't get out and get an attendant unless someone was living with me and taking care of me. My girlfriend agreed to move in, until I got Outreach and an accessible apartment. Then I was lowered on the Outreach waiting list, since I had someone to help me. In June, I finally got Outreach, but there was no accessible housing. Now accessible housing is available, but not the attendant. I'm caught in the middle." (Consumer: Waiting List)*

Some people are less bothered by rigid eligibility criteria because their service providers stretch the guidelines when necessary.

> *"I think that there is a real problem because the eligibility criteria are quite narrow. It's only because the co-ordinator here interprets them broadly that we're able to be so flexible. If only everything could be a little less bureaucratic!" (Service Provider)*

> *"Staff are very dedicated, sensitive to issues of consumer control and willing to do whatever they can to meet the needs of people. But often what they have to do is outside the boundaries of what is supposed to be happening, according to the guidelines." (Consumer Leader)*

Back-up System Required

The feeling is that many people who require a high level of supports, such as those with high spinal cord injuries, would not want to live alone with Outreach where there is no back-up system.

> *"We have one guy who chokes and has a pull cord at his bed. We have to be there in seconds. And others need toileting. Most people who choose Outreach could do without if they had to. There is no question people in Outreach are more at risk. It's very difficult to provide back-up service." (Service Provider: Outreach)*

Many people believe this need for security is a strong rationale for maintaining many components of the SSLU projects, especially the 24-hour back-up support. The feeling from many others, however, is that there should be an option for those who have a back-up, like a parent, spouse or friend, or simply for those who feel taking a risk is their personal choice. Some concern was expressed that to restrict the Outreach program to only those who have a back-up is discriminatory, unless the program will assist people in developing back-ups.

> *"I believe that I could live in a project or with someone because there are models, like Creekview in B.C. where 6 respirator dependent quads with C1 level lesions live." (Community Meeting)*

> *"There are people so desperate for support services that they lie about having back-up service. But where do you get a back-up service? This is a severe problem...that stipulation of having no back-up system means no Outreach. If this is a MCSS stipulation, then MCSS should pay for it." (Community Meeting)*

Some people talk about using their friends at school and work as a way of having a stronger sense of community around themselves, yet others feel they want to keep friendship separate from attendant care. (Community Meeting)

Further, there was some feeling that people with other kinds of physical disabilities, such as visual or hearing impairments, are being excluded from service. (Consumer Leaders)

> *"I would like to see the criteria for attendant care expanded to include other disabilities. People with hidden disabilities may need the support just as much as people with obvious physical disabilities." (Community Meeting)*

> *"We tend to categorize people too much. Services are available only to each group and you have to fit into one of those categories or niches. What happens when you don't fit into one of those groups? And we hope that people aren't losing out in getting services because the services are inappropriately labelling." (Community Meeting)*

> *"I have visual problems but that doesn't qualify me to get support care. I have a problem with transportation and being robbed of my independence. I don't qualify for the parallel bus. I can't see well enough to do a good job of housecleaning so I have to hire a housekeeper." (Community Meeting)*

> *"There are people with polio, emphysema and asthma who are disabled but don't get care because the government doesn't recognize them as being disabled ." (Community Meeting)*

Directing Own Care

The Ministry guideline which states people receiving Outreach must be capable of directing their own care is raised as an issue in several places. Generally, Outreach is perceived as a service for people who want strong consumer control and thus need to be able to direct their own care. Those seen as being unable to direct their own affairs, such as individuals with additional emotional or developmental handicaps, are not generally served within SSLU projects. This raises the issue of more severely or multiply handicapped people who have family members, friends or advocates who could assist the person in directing their own care.

> *"I want my son to continue living at home with me but he can't get the support here because he has trouble making decisions." (Parent: Community Meeting)*

Many people are questioning whether people with multiple disabilities should be served in much smaller or more independent housing, particularly if supports are made available. While there is generally the feeling that people with greater needs would want to have services that are more centralized for faster and easier access, this does not have to mean institutional-like care. (Consumer Leaders; Community Meeting; Consumers: SSLU).

> *"There are handicapped people who need total care. I feel that there should be a comfortable environment for them as well. We need more projects to allow people to live on their own no matter what the handicap because institutional life is no life at all." (Consumer: SSLU)*

In a submission from the Attendant Care Action Coalition to the Review, it was reinforced that people who are capable of directing their own care, those who are capable of becoming able to self-direct, and those who will never be able to direct their own care should all be served by Outreach. But they feel that there may be a danger with this process:

> The Outreach program is developing policies appropriate to those unable to direct their own care, with a commensurate and regressive erosion of consumer control. Although recognizing that all categories (of consumers) have attendant needs, it is imperative that self-directed consumer control not be diluted or infringed upon in order to adequately meet the service needs of those unable to direct their own care needs. (Attendant Care Action Coalition, 1988)

Views shared at a community meeting reflect what many people expressed during this Review:

> *"Individuals are encouraged to find and hire their own attendants. The assumption is that people are able to direct their own care, but we feel that even if they're not they should still be able to take advantage of this program."(Community Meeting)*

An interesting local interpretation of the Ministry policy which says "service providers must be responsible for assessing applicants' eligibility and obtaining and verifying information pertaining to the extent and nature of the applicant's disability", has occurred in some communities with people with deteriorating conditions.

> *"Some SSLU and Outreach projects are making...clients who direct their own non-medical physical attendant assistance*

submit to a third party medical evaluation and unconditionally release confidential medical information to the service provider. It is deeply insulting and offending to be forced into such an evaluation. It must be remembered that a physician serves his or her patient, not the agency. This medical form requirement runs counter to the philosopy of our times. It is possible this came into being because of an administrative need to develop a mechanism for selecting only candidates who are able to live independently. But the medical form, in addition to its insult and offensiveness, does not adequately address the screening needs required." (Consumer: Outreach)

Age Restrictions

A few people note that the current age restrictions on both support service programs were creating problems.

What about kids that leave home at age 15 or 16; they should be able to access the service ."(Service Provider)

Other people were more concerned about the continuity between children and adult programs. (Consumers: Outreach; Service Provider Parent: Community Meeting)

"Attendants are available for kids but not adults. Within the kids' program, services are in place for disabled kids in school." (Service Provider)

"Right now we are getting support for our foster son through Special Needs at Home funding. But it would help us tremendously if we knew that at age 18 he would have a guarantee of these funds being continued through Outreach. Some continuity between child funds and adult funds is really needed. The future is so unknown and it is incredibly frustrating running from agency to agency. We are always caught between criteria."(Community Meeting: Parent)

The issue of older people who have physical disabilities was raised as part of these discussions. In particular, an increasing number of seniors are applying to and using SSLU and especially Outreach.

> *"Many people with disabilities are aging; their needs are identical but the services for seniors aren't as comprehensive. But SSLU has an age limit of 65." (Service Provider)*

> *"It's a catch-22. They need the assistance too...the whole function of Outreach is to allow people to live independently in the community wherever they want to, but half my client group is probably senior citizens. Frequently they don't need that much care, as much as support and companionship. But if there is only a limited space available, it's given to younger people." (Service Provider)*

> *"Disabled people who are seniors and disabled from birth are discriminated against. They are not accepted into nursing homes or seniors residents, especially if they have speech problems." (Community Meeting)*

Family Status

While the Ministry guidelines do not mention anything about restricting people with certain marital or family situations, certain projects appear to have some restrictions that put a great deal of stress on individuals.

> *"I can't have my kids live here with me."(Consumer: SSLU)*

> *"I know of married couples who can't live together because of the guidelines. There are so many contradictions. We say that we want to help but we impose so many rules that we are not helping people stay together." (Service Provider)*

> *"This new 'spouse in the house' ruling is scary for us to look into. My girlfriend, because she has a good job, will have to take on responsibility for me. My FBA and benefits are affected." (Community Meeting)*

RESTRICTIVE POLICIES MAKE IT DIFFICULT TO HAVE NEEDS MET

Once individuals are involved in either Outreach or SSLU projects, there are several policies that many consumers feel inhibit their needs being adequately met. The two policies most frequently criticized are the policies which limit the role of attendants to do largely personal care, and too few and inflexible hours. These issues will be discussed at length in this section, as well as one smaller but not unimportant issue around who can be hired to be an attendant.

The Limited Mandate of Attendants

The Ministry's regulation that attendants should be used primarily for personal care has been interpreted by most communities to mean attendants cannot provide support outside the home. Even within the home, there are many things people feel attendants should be allowed to do that they currently do not. Since most communities follow the guidelines to a large degree, our data indicate that many individuals are seriously affected by the limited mandate of attendants:

- the person must stay at home, isolated and lonely.
- sometimes the person's nutrition, health and independence is affected.
- the person must rely on friends, relatives or reliable volunteers to either do errands in the community or accompany the individual.
- the person must go to costly personal expense to get support in the community.

> *"There are lots of problems with the limited duties of Outreach attendants. You really need them for a wide range of duties rather than personal care only." (Consumer: Outreach)*
>
> *"The fact that the government says that the money should just go for personal care is ludicrous. Just because my body is clean...that's not enough. I need my environment clean." (Consumer: Order-in Council)*
>
> *"The Ministry says they want us to support people in being independent but then the dollars haven't followed to enable us to do this." (Service Provider: SSLU)*
>
> *"MCSS could expand their financial contribution four times and thus get at core needs in a greater way. If attendant care was*

> *expanded to more settings like work and social areas, then people could grow." (MCSS staff)*

Some people believe that part of the problem for Outreach is that the concept was really poorly defined in the first place. The feeling is that much clearer guidelines are needed.

> *"Outreach is a supplementary program which tends to work well for people with stable disabilities, but not so well for people with deteriorating disabilities. The problem is that Outreach is ill-defined and is translated primarily from SSLU rather than from a home support policy. It was poor policy right from the beginning." (Service Provider)*

> *"Any new act should be generic. Guidelines need to be tightened up. But the problem is not the guidelines but the interpretation. For example, it's not in the guidelines in other than the person's home, but that's how it's being interpreted." (Service Provider)*

> *"The guidelines need to be revised. There are certain expectations but we need a generic manual including program evaluation and monitoring systems." (MCSS staff)*

Table 9 shows the major areas to which consumers feel that attendant care support needs to be expanded.

The survey data indicate that approximately 30 percent of consumers perceive the need to have their attendants provide support for employment. As noted elsewhere, the majority of the consumer respondents were unemployed. These figures on the need for support for employment raise the question about how many of our respondents are chronically unemployed either because of their disability or because they have given up hope of ever finding a job. This would certainly influence their views on attendant care in the workplace.

The data also show that a minority of consumers perceive the need for attendant support for parenting, while larger numbers of consumers see the need for expanded attendant services for education and vacations. This data is confirmed by the qualitative interviews.

Table 9

Consumers' Perceptions that Attendant Care Needs To be Expanded

	Not necessary (%)	Desirable (%)	Essential (%)	Total N	Total (%)
Employment	72.1	19.8	8.1	86	100
Education	68.2	15.9	15.9	88	100
Vacations	34.1	46.6	19.3	88	100
Parenting	82.6	14	3.5	86	100

Work. Several consumers in most communities talk about the importance of extending attendant care to the workplace if people are going to get out of the home and off pensions. (Community Meetings; Consumers: SSLU; Outreach & Waiting List; MCSS Service Provider: Outreach and SSLUs; Consumer Leaders). There seems to be a discrepancy in that if the person has a Vocational Rehabilitation worker s/he can get an attendant in the workplace, but not if they get one through Outreach. (Community Meeting)

> *"I need attendant care in my employment, at lunch, in the evening and in travel with my job. I have to hire people to help me at my own expense." (Community Meeting)*

> *"No two people's needs are the same, so the guidelines need to be expanded. I need someone to put the paper into my typewriter, but nothing else as my mother does everything except my physcial care." (Consumer: Outreach)*

> *"Since I can only get Outreach at home, I must go home at lunch, the van is on time, go home to meet my attendant and go to the bathroom, have the van come back and get me and hope I'm not late for work - even though I will of course have missed lunch." (Consumer: Outreach)*

> *"I need an attendant to travel with me for my work. I must go and inspect nuclear related jobs. But I can't stay overnight. Everyone else does but I have a co-worker right now who is willing to bring me back. If I'm going to a conference I need to be able to call ahead or take someone with me. The latter would be better because you never know what you're going to run into in another country." (Consumer: Outreach)*

> *"I used to work for an oil company but I couldn't keep the job because I had to leave at 3:30 to go home for attendant care." (Community Meeting)*

School. A number of people talked of the importance of having the chance to return to school, either because they missed the opportunity when they were younger, or for self development. They feel that for this to be possible, people who need assistance need attendant care duties expanded. (Community Meetings; Consumers: SSLU, Outreach & Waiting List; MCSS staff; Service Providers: Outreach & SSLU; Consumer Leaders).

> *"Some universities have staff on campus, with students as supports. At Humber, SAC pays students on campus as readers, writers, toilet helpers, and feeders. Some colleges also have attendants available. In the city, we have five adult basic learning programs but only one has attendant care. (Community Meeting)*

> *"There are a lot of young anxious people moving to this co-op from institutions. There needs to be more support for them, especially if they are going to be going to school." (Service Provider: SSLU)*

> *"If I had an attendant to take me to school I would have hope for a future. Where does my life begin and end? It makes you very depressed seeing the same walls day in and day out." (Consumer: Waiting List)*

Travel, Vacations, and Social and Community Outings. Attendant care support in the area of recreation and vacations is seen as being particularly important for people's personal growth. (Consumers; MCSS staff; Service Providers). The fact that this area is mentioned more often than employment or education may be a reflection of the perception of many disabled people that they no longer have options to work, but still have the desire to be active in the community.

> *"I want more independence and community involvement, but I'm not sure how an attendant could help me. I would like to have someone assist me to figure out how to be more part of community life." (Consumer: Outreach)*

There was some hesitation about using friends for large attendant tasks, such as travelling and vacations.

> *"It's a big mistake relying on friends for attendant care support on vacations. It wears them thin. I find travelling is hard on friendships anyway. You have to get up and go to bed at the same time. The best things is to hire someone and pay their fare if they'll do this and that." (Consumer: Outreach)*

> *"On weekends I go home to my parents in Niagara Falls. They don't have Outreach, so I have to use VON for partial service. I don't want to have to fall back on my parents." (Consumer: Outreach)*

Generally there is a strong feeling that support for banking, shopping and other activities of daily living should be made available. (MCSS staff; Service Provider).

> *"It would be nice if when my wife's birthday came up I could have an attendant to go shopping with me for an hour." (Consumer: Outreach)*

> *"It's the whole idea of a social outing. People need to go out into the community and do their own shopping and things, rather than have them all done for you." (Community Meeting)*

Attendants, through the survey, indicate they spend 5 percent of their time supporting consumers outside the home (see Table 10). While this limited support appears to have been helpful (Attendants: SSLU's), because of the restricted hours, most communities find it is more economical to have volunteers or friends carry out this role. (Service Providers; Consumers: Outreach; Community Meetings; Service Provider: Outreach).

Table 10

Attendants' Estimates of Their Job Responsibilities

Area	% of their time
Personal care	50
Meal preparation	19
Light Housekeeping	14
Communication assistance	6
Supporting person in the community	5
Other	6
TOTAL	100

Housekeeping. One area not yet mentioned, but related very much to the social area is that most attendants will not clean someone else's mess. (Consumers: SSLU). They will only do light housekeeping (14 percent of their workload) which is solely that of the consumer. On surface this sounds logical, but so do people's complaints. Consumers end up hiring staff from Integrated Homemakers for their daily housekeeping, contributing again to fragmentation. One person who works during the day, however, said she did not qualify because she was not home during the day. (Consumer: Outreach).

> *"When we have company, they (attendants) expect our company to cook, clean up and do other cleaning chores left undone from last week (dishes). I have lost friends because they know that when they come they have to clean or they feel guilty. If they clean they resent having to clean last week's mess and if they don't clean, they know that it will be left there for another week. You feel rotten because you are using your friends and you*

> *don't want to and you know that they won't come back." (Consumer: Outreach)*
>
> *"I'm a home owner. My house is deteriorating. I need help with my house maintenance, not just inside but outside." (Consumer: Outreach)*

According to the Outreach guidelines, attendants are not allowed to do light housekeeping because Homemakers can do this service.

> *"But this is not normal ...functioning persons do all these tasks themselves in a flexible, integrated and efficient way. This causes an increased burden in terms of having to relate to several different people, organize one's daily schedule around them, separate out functions and it increases costs and reduces efficiency...it prevents people from maintaining employment." (Consumer: Outreach)*

Parenting. Our survey data demonstrate that 17.5 percent of the respondents feel that it is either desirable or essential for them to have more personal support in the area of parenting (Table 9). Some interesting insights were gained on this topic from consumer leaders and at the community meetings.

- The dilemma is that parenting is interpreted as being child care, which attendants will not do, instead of assisting the person to be a parent. This concept of being an extension of the person, doing what the person would do if he or she could do it themselves, is one that consumers feel is an important shift in thinking that is needed.

- If there is a child involved, this may require more than 3 hours a day of attendant care.

- Once a child is one year of age, the person cannot be expected to live in a one bedroom apartment, which is very hard to find.

Portability. Finally, a small but significant number of people feel very frustrated and fearful of the future in case they need to move to another community and need to begin the process of trying to access services all over again; for example, like changing communities in order to go to university. They lose their current service and could be on a two-year waiting list for new service. (Consumer Leaders).

> *"People want to move to different cities, to take vacations; at the moment there is no way to protect a person's space if they leave or change locations." (Service Provider)*

Limits on Who Can be Paid to be an Attendant

Several family members and people who live with relatives feel that family, friends or neighbours should be able to be paid as attendants, because of the resulting convenience and flexibility. (Community Meetings; Consumer Leaders; Service Provider). The guidelines for Outreach say that relatives cannot be hired.

> *"I think the opportunity should be given to these people to maintain their dignity and hire relatives if they prefer." (Consumer Leader)*

> *"Workers' Compensation, as well as programs in other countries, actually encourage the employment of family members because they have proven there is much greater commitment and quality of care. Why is this a forbidden option? This restriction personally eliminates three potential attendants who would be willing to help me out. Their only crime is one is a sister-in-law and two are nieces - not to mention the personal sacrifice of my live-in elderly parent who will likely continue to provide this essential unrecognized service for as long as she is able." (Consumer: Outreach)*

In some cases, people are willing to leave their jobs and stay home if they could be paid.

> *"One man who will die within 6 months requires palliative care and wishes to remain at home. A brother is willing to work part time for his brother for the next 6 months if an agency would hire him". (Service Provider)*

> *"In another case, a man who recently got MS is so ashamed and upset to have different people coming in all the time doing his bowel and bladder routines. His wife is willing to quit her job and provide his care if she could be paid." (Consumer Leader)*

In some cases, exceptions have been made, and family are hired. This mostly happens in rural areas, out of necessity.

> *"In very special cases, relatives are employed. The guidelines say no but in some cases in remote areas, everybody is related so you have to hire who is available." (MCSS staff)*

> *"We are flexible, willing to go beyond MCSS guidelines, if it's really necessary. Once we paid a wife who was a nurse - because that's what he needed." (Service Provider: Outreach)*

A few people raised concerns about the idea of changing the policy to allow family to be attendants. Some were worried about the effect this could have on relationships. (MCSS staff)

> *"I think it's a drastic mistake because when you're living with someone, you're at their mercy. When you pay for that, you take away the strength of family support. If you purchase the service from Outreach, you're supporting family members, lightening their load; so support the family, but don't pay them as caregivers." (MCSS staff)*

> *"I think that there are a lot of problems with families doing their own care. There is family breakdown and physical exhaustion. It takes pressure off the relationship to have an outside worker coming in. It's not just personal care we do...we give moral support to both people." (Service Provider: Outreach)*

> *"There is a lot of confusion in roles when the spouse has to do personal care support and be that person's lover and best friend." (Community Meeting)*

Another caution expressed is that if such a policy became widespread, there is the danger that young disabled people may not be encouraged by their parents to live more independently in the community.

Too Few and Inflexible Hours

The three-hour limit on Outreach services is a problem for many people who are already receiving service, as well as for those who, because of their high needs, are unable to access the program.

While it seems to be adequate for many of those presently served, interviews reveal that many people feel they are receiving a bare minimum of service, which makes it difficult for them to have any flexibility or quality of life. Thirty-four percent of Outreach consumers, when asked in the survey, indicated they could benefit from additional hours of Outreach. Furthermore, 42 percent of Outreach respondents would like to receive additional days of support services; 22 percent of those who receive services less than 7 days each week would like support services everyday of the week.

For those consumers who have strong social networks, meeting these support requirements is clearly less of a problem. In general, however, people feel the program should not be restricted in hours, so that if someone really wants to live on their own instead of in a project or institution, it would be possible. (Consumer Leaders; Consumers: Outreach). Even with hours combined from other services, many people still do not feel they have enough. (Community Meeting).

> *"For the clients in the community who have been given 10-28 hours a week and designated as light care, most of them really need more hours. But they get a certain number of pre-planned hours. We need more flexibility to provide the correct amount of care." (Service Provider)*

> *"I have applied to every SSLU in town because it takes too long to do all of my personal care. Ideally I would like to stay put in this co-op. I work and find the Ministry guidelines for time also too small. Often midnight is too early to not receive service. So currently I receive no night service - which I could use. There needs to be a nightshift." (Consumer: Outreach)*

> *"It is important to increase the number of hours of Outreach but 24-hour home care is not realistic - its cost would be prohibitive. We need individual assessments and services provided based on real individual needs, instead of arbitrarily choosing a number of hours." (MCSS staff)*

Most people are in the position of having to make trade-offs and actually have many basic needs unmet. Sometimes the problems around shortage of time are exacerbated by the inflexibility of the hours and activities. For example, a person may have to choose between a bath and going to a meeting, but since the bath can't be rescheduled, the meeting is missed. This problem occurs in both Outreach and SSLU. (Consumers: Outreach & SSLU).

> *"People are needing more hours of attendant care. There are consumers not here tonight because they are restricted in what they can do with the few hours of care given." (Community Meeting)*

> *"If the hours could be spread throughout the day, more flexible, Outreach might work for her. She can be alone for 3 or 4 hours but then needs help with her leg bag lying down for an afternoon rest, and plugging in the electric battery." She would like to stay at home; it's a good neighbourhood, she has a garden with a patio, and a dog. But she needs more hours and they have to be more flexible." (Service Provider)*

When hours are so limited, it means that services are not in a position to respond if a person's needs change or in an emergency, especially if they are in Outreach. (MCSS; Service Providers; Community Meeting; Consumers: SSLU; Consumer Leaders). The very real possibility of institutionalization lurks over people, especially those with multiple sclerosis and other changing conditions. (Consumers: Outreach; Consumer Leaders)

> *"Funding is somewhat of a problem because we cannot change levels of support easily. There is little flexibility to address a crisis or emergency issues." (Service Provider: SSLU)*

> *"If a person has MS and is undergoing a regression, they may be temporarily unable to direct their own care. What do I do? Ship them off to a hospital and take away their self actualization, their independence? They need the support and security and milieu of home." (Service Provider)*

One suggestion is that they use the hours that staff accumulate when a client is away or sick to provide care to someone else when their needs increase temporarily. (Service Providers; MCSS). This is what some service providers are doing under the table. Alternatively, there is the feeling that people should be able to bank their hours for when they will need more, such as for a holiday. (MCSS staff; Consumers: Outreach).

High Physical Care Needs. In general, people with very high physical care needs have difficulty having their needs met by either SSLU or

Outreach. (Service Provider; MCSS; Community Meeting; Consumer Leaders). Outreach was never intended, for example, to serve people who require over three hours a day or who have medical needs that cannot be met by current community services.

> *"Currently there are no supports available for those whose needs are higher. They're still institutionalized because there is nothing here for them." (MCSS staff)*

> *"We deal with a lot of respirator-dependent quads. There are few SSLU's who will accept them." (Service Provider: Community Meeting)*

> *"I applied for Outreach but was refused because they said my needs fell into VON. I would have to sign a release of responsibility." (Community Meeting)*

A review of a random selection of applicants for Orders-in-Council is a source of data which strongly suggest that current support services are not meeting the needs of people with high physical care needs. Over the last few years, fifty-five people have been turned down in their requests for Orders-in-Council. While many of these consumers with high care needs are now receiving Outreach, all the people who were interviewed are finding it inadequate to meet their physical needs.

> *"The present Outreach does not meet my needs. I need someone during the night, during business trips, and during vacations. I've had to hire my own additional person." (Consumer: Outreach)*

The limited support received by many of these individuals with multiple needs puts acute stress on them and on the people in their networks. A 28 year-old woman's situation was typical.

> *"I have been fighting a long time for one extra hour of attendant care to help in the evening. It would relieve a lot of undue pressure on my mom who is my only relative and lives quite a distance from here." (Consumer: Outreach)*

A middle-aged professional noted:

> *"Fortunately, with my wife working, we have been able to avoid poverty, but it has cost us $50,000 a year to hire and maintain attendants and renovate our house." (Consumer: Outreach)*

It is difficult to judge exactly how many more hours individuals with multiple needs might be able to utilize in order to increase their independence. However, the data indicate there is no simple answer, but rather supports must be individualized according to need.

RESOLVING DILEMMAS CREATED BY RESTRICTIVE GUIDELINES

Lessons from Recipients of Orders-In-Council (O-I-C)

More than sixty individuals have applied to receive funding from an Order-In-Council (O.I.C.). Most of these people had been unable to access support through SSLU's or Outreach, either because of long waiting lists or because they are not eligible. Those few individuals whose applications have been successful are very happy with the funding because it allows them to have an attendant, with no fixed upper limit on the number of hours. The recipients who were interviewed are particularly pleased with the role their attendants play. In most cases, people with Orders-in-Council hire their own attendant to perform a variety of functions. Although 65 percent of the work involves personal care, attendants also do cooking, household duties, shopping with the person supporting the individual on outings into the community and at work. As the data suggest, this broader role for the attendant seems to be very important for people with multiple or complex disabilities.

Since the legislature has approved so few Orders-In-Council (13), there is a long list of people who have been rejected (56), not to mention the number of people who get discouraged and will not even try, but are still living in institutions or depending totally on families. While there are some concerns about O-I-C, it is admitted that it seems to be one of the few ways of meeting the community needs and wishes of people with high or complex needs. (MCSS staff)

Creekview Evaluation

A recent comprehensive evaluation of a support service in British Columbia makes a valuable contribution to our consideration of the issues related to individuals with multiple needs (Ryan and Wiggins, 1987). Creekview 202 is a cooperative home project in Vancouver which houses six men with high spinal cord lesions, five of whom are respirator dependent. The evaluation of this project, which functions somewhat similar to an Ontario SSLU, was quite positive:

- costs to the provincial government for supporting these residents are substantially lower at Creekview than at a chronic care hospital.
- despite some individual variation, the overall health status of the residents appears to be at least as good at Creekview as their previous residence, the hospital.
- all indices used to assess standard of care indicate that an adequate standard of care is being provided at Creekview.

The segregated nature of the Creekview project has some problems as a model of service delivery; nevertheless, the finding that people with complex needs can live successfully in the community at less cost than in an institution is quite instructive.

Attendants in Neighbourhoods

One solution to the problem of lack of flexibility around individuals' schedules, particularly for those who require several short periods of support spread throughout the day, is using neighbours as attendants. This might be particularly useful for individuals who are mainly interested in very part-time work.

> *"I receive a tuck-in service at night. My neighbours who do this do not need to be specially trained." (Community Meeting)*
>
> *"My neighbour has been doing this and I don't want someone else - who can only come 5 days a week in blocks. Having my neighbour has a tremendous impact on me because I have flexibility. If I'm having a good day, I don't need her so much, but if it's a bad day, I need her more. She knows all this and is*

> *more than willing. I've trained her too. Why should I have to start all over?" (Consumer: Waiting List)*

This could also be a solution for those who supposedly need too little support to warrant an attendant.

> *"The joke is that a person might not only not get in to Outreach because their needs are too high in terms of hours, but in my case, I was told I had to use it for at least 1 hour together which I didn't need so I was left no alternative but to apply to an SSLU." (Community Meeting)*

SUMMARY AND RECOMMENDATIONS

The findings outlined in this chapter will be briefly summarized and related to possible policy and program changes.

The eligibility criterion which restrict access to the Outreach program are a problem for a variety of reasons which have been presented. Resolving these dilemmas, however, is not a simple matter of changing the wording on each criterion. Rather, it appears that each area of concern needs to be carefully analyzed in terms of the potential impact of changing the eligibility criterion.

First, the minimum age of 18 seems reasonable, especially now that children with a variety of disabilities can access the Special Services at Home Program. While it is recognized that this program is limited in its hours and functions, it probably makes more sense to expand the Special Services at Home age criteria than to expand the Outreach program to cover children and youth. An attendant care program which serves adults and children would not be as coherent, either philosophically or pragmatically, as one which serves just children or just adults (Wolfensberger & Thomas, 1983). Policy options, however, must be developed so that youth who turn 18 are not suddenly left without any support service. This is a crucial age, when many disabled people in the past have had few opportunities to become independent, but rather have been forced to continue living with their families. In addition, more effective school to work supports are needed to avoid a future of unemployment and dependence.

It is therefore recommended:

21. **That youth with physical disabilities who are receiving Special Needs at Home funding be transferred to the Outreach program when they turn 18 if they require attendant care.**

22. **That the Ministry of Community and Social Services, in collaboration with the Ministries of Education, Labour, and Skills Development develop a comprehensive initiative which will impact upon the transitional issues affecting youth (16-21) with physical disabilities.**

Second, the Outreach eligibility criterion that consumers must "be able to direct their own care" creates a policy dilemma when considering how to provide support to people with multiple needs in their own homes. On the one hand, removing the criterion might mean that Outreach could be provided to a broader range of consumers, including those who, for whatever reason, are unable to direct their own care.

On the other hand, removing the criterion might also open up the possibility that services could become paternalistic because the current assumption and safeguard about consumer direction and control will have been eliminated. The data show that some service providers are somewhat controlling, which suggests that eliminating this criterion could produce more problems than it solves.

From a policy perspective, it probably makes more sense to maintain the eligibility criteria that people have to "be able to direct their own care". In fact, as many consumers emphasize, agencies need to start with this assumption for all consumers. Then, if it becomes clear that an individual consumer is unable to direct his or her own care, support can be provided. The support should take the form of an independent advocate, who is knowledgeable about that consumer's situation and is available to represent as closely as possible the "person's needs and interests." It has been shown that, over time, individuals with seemingly very multiple disabilities develop ways of communicating their needs and preferences (Lovett, 1986). Sensitive service providers and personal advocates must ensure that people's capacity to communicate is maximized.

The focus needs to be more on finding ways of supporting people in learning how to direct their own care. In Manitoba, for example, each person who receives money for attendant care is given the option of attending courses or receiving individual support on how to direct their own care from the Independent Living Resource Centre of Winnipeg.

It is therefore recommended:

23. That a broad definition of "directing your own care" be developed to include a component of support for those who need it; and that this new definition be adopted by the Ministry as a training tool for both individuals and attendants in learning how to "direct one's own care".

24. That a method to support those consumers who need assistance in directing their own care be developed; that independent personal advocates be used to ensure that rights are being safeguarded; and that independent groups, such as independent living centres, be utilized as sources of support and advocates.

Another eligibility criterion needing review is the one pertaining to Outreach applicants requiring a back-up system. This Review has shown that many people feel this policy discriminates against those with weak family ties and social networks. This criterion currently eliminates many people and encourages others to be dishonest in order to access the service. The dilemma is, however, that by eliminating this criteria, the program runs the risk of leaving some people stranded with a minimum of care. Therefore, it is recommended:

25. That the requirement that the consumer have a back-up "be eliminated" as a criterion from the Outreach program; and that individuals who lack a back-up system be given assistance to develop a support network as part of their independent living service.

The final area related to eligibility criteria relates to policies which restrict families from remaining together in order to access support services. The results from this Review have shown that many individuals are put in the position of having to leave their parents, spouses and young children in order to get attendant care support. The impact of this kind of policy results in incredible loneliness and anger, not to mention permanent effects such as family breakdowns. It is therefore recommended:

> **26. That any SSLU policies, either at the Ministry level or in local interpretation, which force families to be split up in order to access service, be immediately eliminated; that any future SSLU projects include plans for family units; and that in the interim period, such consumers be eligible for Outreach services to enable their families to stay together.**

Third, many consumers who need assistance at work, school, on vacation, or while parenting express strong support for expanding attendant care to these areas. The data again point to the need for individualized support services. Relatively small numbers of consumers indicate that it would be "desirable" or "essential" for assistance to be available for parenting, work or education/schooling. Yet for these people, expanding the availability of assistance will significantly increase their sense of personal control, independence, and community integration. In the area of work, the argument has been made that if disabled people are gainfully employed, they will no longer "cost" the welfare system and will become tax paying citizens (Symington, 1983; Wehman, 1981). Several consumer leaders argue that this is a strong rationale for expanding attendant care to the workplace for those who need it. Adolf Ratzka, a consumer leader and researcher from Sweden, has written that "Attendant care services are the very key to a dignified and productive life in the community" (Ratzka, 1986, p. 8).

The Ontario Advisory Council for Disabled Persons recently recommended that independent living assistance be "available in all settings of daily life: at work, at school, on business trips, for recreational activities and vacations" (Ontario Advisory Council for Disabled Persons, 1988, p.27). They argue that this recommendation is consistent with the government's goal of ensuring that disabled people can participate more fully in the mainstream of Ontario society. (Consumer Leader: Community Meeting). This position is shared by the World Institute on Disability in *Attending to America: Personal Assistance for Independent Living*.

> Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for

themselves if they did not have a disability (Litvak &Heumann, 1987, p.27).

Similarly, the Attendant Care Action Coalition (1987) has recommended that consumers be able to apply for an independent living allowance which could be used in any setting required by the consumer.

The policy option which best responds to the data and the foregoing analysis obviously involves some expansion of the availability of attendant care. Adding the two items which are primarily within the home (housekeeping and parenting) may mean additional hours for the consumer. But a more comprehensive policy option is needed which would consider some way of combining attendant care with the housekeeping function, which currently fall under the mandates of separate agencies. In Chapter 8, we review that dilemma in depth.

The other areas for attendant care expansion primarily fall within the community: school, church, workplace, etc. In most of these settings, the demand for personal assistance is quite limited. For example, typically at work, a severely disabled person may need assistance for 15-20 minutes in the morning and again in the afternoon. A small number of Outreach agencies have already found creative ways to support people at work and the actual time involved is not extensive. The workplace is an ideal setting to hire a co-worker to assist with personal care or to have an Outreach attendant visit the workplace as part of an overall schedule of home visits. Again, it is vital to reiterate that any expansion of the availability of the attendant must continue to be consumer directed.

Based on the data and analysis, it is recommended:

27. That attendant care be available in settings outside the home in which the consumer requires personal support such as at work, at school, while on outings into the community, or on trips (either pleasure or business); and that the Ministry phase in such a policy initiative on a demonstration basis.

From the data, it can be seen that there needs to be greater flexibility in who can be hired as attendants. In other jurisdictions, it has been shown that there has been tremendous success in projects where individuals are able to hire their own support people, whether it be neighbours, friends, or relatives. Already a few Outreach programs in Ontario are having success with using neighbours and finding it allows for greater flexibility in scheduling.

While there needs to be some caution in the area of hiring family members, it seems that the policy needs to be flexible enough to allow it in extreme situations where this is actually the most appropriate alternative. The fear that we should not be encouraging family members to be paid for things they would normally do anyway is not a difficult barrier to overcome. Like any other person, the individual is assessed by Outreach to determine the amount and type of support required. The family member providing the service would be remunerated for whatever hours would have been covered by outside attendants. Therefore it is recommended:

28. That the Outreach criterion restricting relatives from being hired as attendants be eliminated; and that Outreach programs be encouraged to provide options for consumers, ranging from the use of full-time agency staff to part-time neighbours or friends as attendant care workers.

The three hour per day maximum restriction on attendant care services in the Outreach program is adequate for a great many people, but at the same time has served to eliminate many people who want this kind of a service from the program. Consistent with the recommendations in Chapter 5 on expanding services, and in Chapter 3 on individualizing support services, it is clear that this restriction needs to be changed. Eliminating a maximum number of hours, particularly one that is so low, would provide greater flexibility to service providers in responding to emergencies, would provide real choice to individuals, and would result in less institutionalization. It is therefore recommended:

29. That the 3-hour restriction in Outreach be eliminated and that a more flexible system of assessing needs and providing support service be implemented on an individual basis.

30. That there be no minimum time requirements, but that individual funding be encouraged as a way of enabling people with erratic or very low scheduling needs to be accommodated.

31. That a pilot project be initiated in order to learn how people with very high physical care needs,such as respirator-dependent quadraplegics, can live independently with attendant care support.

Chapter 8

RECEIVING SUPPORTS FROM MULTIPLE AGENCIES

The focus of this Chapter is on the concerns people have about receiving support services from several agencies and the lack of overall co-ordination among the agencies which provide support services.

At first this appeared to be a concern largely for Outreach consumers, many of whom receive services from three providers such as Outreach, Integrated Homemakers, and Red Cross. It then became clear that it is also a concern for many SSLU projects who purchase attendant care from outside agencies either as a regular or back-up service.

The main findings which have emerged in this study are:

1. ***Individuals receiving support have concerns about receiving their support services from too many agencies.***
2. ***There is a lack of overall co-ordination among all agencies which provide support services.***
3. ***Many individuals receiving support, as well as SSLU and Outreach agencies, are not satisfied with many aspects of these outside agencies.***

Each of these three major issues will be discussed in the remainder of this Chapter. In each section that follows, people's suggestions for resolving dilemmas created by receiving services from multiple agencies are included.

TOO MANY AGENCIES IN ONE PERSON'S LIFE

In the consumer survey data, 52 percent of the respondents indicate they receive their services from several agencies. In the interviews, most individuals receiving support services talked about the problems of having multiple service agencies providing their essential personal, medical and home services.

Difficulties With Too Many Agencies

Consumers and service providers identify numerous difficulties with comsumers receiving support services from several agencies.

Lack of Consistency and Continuity. People feel fragmented when they have to get support from many different agencies. They say it is difficult to feel any sense of consistency or continuity in their lives when three different people, from three different agencies, are coming into their homes each day or several times a week. (Consumers: Outreach &Waiting List; Service Provider: Community Meeting).

> *"It would be better if all services came from one agency. Each defines what they do and we get caught in between. It's too bureaucratic." (Consumer: Outreach)*

> *"I don't really care where the service comes from as long as it is good. It seems to be better with Outreach so I would like everything from there and not have to get it from Red Cross. I'm not aware of any legislative problems, but if this is it, then it needs fixing." (Consumer: Outreach)*

Most people on the waiting list for Outreach, for example, are already getting some service from two different agencies. Many consumers feel anger and a loss of dignity because of this lack of consistency between agencies. They, perhaps wrongly, assume that when they get Outreach, they will be rid of the lack of consistency and continuity in their lives. (Consumers: Waiting List)

Lack of Privacy. When a person has as many as three different caregivers a day, there is little privacy for the individual; this problem is compounded when the person has little choice over who those three individuals will be.

> *"Too many services are involved, generating a sense of intrusion, confusion and disorganization. It's hard to keep things organized with all these people coming and going. One person puts things in one place, the next comes and moves things around." (Consumer: Outreach)*

Hard to Feel Control. It is very difficult for consumers or even service providers for that matter, to feel that they have much control over a situation in which there are so many groups providing basic support to the same individuals.

> *"When we have to buy other services, like from Par Med, we lose control." (Service Provider: SSLU)*

Time Consuming. It is very time consuming for the individual to have to deal with a complex array of services, leaving little time or energy for other things. High staff turnover in one or more of those agencies only further complicates the situation. (MCSS staff; Consumer Leaders; Consumers: Outreach).

> *"Families, consumers and service providers are spending a lot of time co-ordinating services. It's very frustrating having a revolving door." (Community Meeting)*

> *"Changes in personnel lead us to continually having to explain the routine. This is very time consuming and frustrating to have to be continually repeating the same instructions. Workers just think I'm 'picky'." (Consumer: Waiting List)*

Since the system is not designed for the individual to do co-ordination, the individual often lacks power and influence, resulting in poor service. (Consumer Leader).

One Person to Provide Support

A few service providers, MCSS officials, and consumers specifically talk about some of the things that could be done to begin to resolve the difficulties resulting from too many agencies in people's lives. Most of the proposed suggestions emphasize that consumers should have only one attendant in their home and have to deal with only one agency.

> *"I would like to see the organizations get together, so in order to get the help you need, you only have to go through one agency. One helper to do my personal support care, as well as the laundry and housekeeping. There would be less duplication and confusion." (Consumer: Outreach)*

> *"IHP and attendant care should be combined. The worker is already in the home and could do the job. Currently the worker can't get enough hours to make it worthwhile, so this would help." (Consumer: Outreach)*

> *"Let attendants do housekeeping. My experience with Homemakers is that it's just a Molly Maid service without the good cleaning-they can't do anything." (Consumers: Outreach)*

Some people are very concerned about the liability issue from the service provider's point of view, and at the same time, with the consumer's right to choice and dignity.

> *"My big dream is having one person do all of the things that I require. It's probably not possible because it takes very special people to do even one of these jobs. Also, you'd have the medical people screaming down your throat....While this would solve the problem of gaps and overlaps and traffic, we don't want to eliminate choice. So let's say we could work out the liability problem and let attendants do catheters or needles, what if the person doesn't trust the attendant and would rather have a nurse? Could a system be designed where it would be the choice of the person to determine if they want one person to do everything?" (Consumer Leader)*

Some groups have consciously tried to only send in one worker, as a way of improving continuity for the person, with positive results.

> *"With SSLU we try to keep the same person going in, as a means of maintaining relationships." (Service Provider: SSLU)*

> *"One man in a rural town gets all his services provided by the same person all day long. Red Cross is not as happy because they can't control, but the consumer is happier." (Service Provider)*

Part of the solution to having fewer people in the home seems to be the idea of having one co-ordinating body, a non-agency approach which would support consumers in accessing what they need. Several people like the idea of having a broker, which is discussed in depth in Chapter 10. (Consumer Leaders; MCSS staff; Community Meeting; Service Provider: Outreach; Consumers: Outreach).

> *"I would like to see a flexible, simplistic system that would take care of most of the person's needs regardless of their disability." (Community Meeting)*

> *"An alternative would be that one agency would be responsible for co-ordinating all home care services - a central figure orchestrating the services. It would be best if a generic agency would play this role - providing services to everybody who needs home support without specifically labelling the service. It would require a whole different way of thinking that many agencies are just not used to." (MCSS staff)*

LACK OF CO-ORDINATION AND COOPERATION AMONG AGENCIES PROVIDING SERVICE

Consumers and service providers in both SSLU and Outreach Programs have many concerns that seem to result from the lack of co-operation and co-ordinated policies around the area of attendant care. MCSS officials admit that most of the services that have evolved in the last decade are the result of a patchwork approach to service development. One official admitted:

> *"We simply don't redesign the system when we incorporate new services or attempt to deal with newly identified needs." (MCSS staff)*

Problems Resulting From Poor Co-ordination

When consumers are involved in receiving services within a system that lacks co-ordination, there seem to be several impacts on the individual.

Not Knowing What is Available. The human service system is very complex and extensive. It is clear, from consumers in particular, that they have a great deal of difficulty knowing where to go to have their needs met. (Community Meetings; Consumers: SSLU, Outreach & Waiting List; MCSS staff; Service Provider: SSLU).

> *"I believe that there is a lack of centralized information for people who need benefits or support, where you can get information and who you get in touch with. You have to make endless phone calls...no one is advised about sources of*

> *education, social benefits or handicappped person's rights."*
> *(Parent: Community Meeting)*

> *"The information centre that exists here...it doesn't address bureaucratic processes and ways of dealing with the system."*
> *(Consumer: SSLU)*

The survey data confirm that many consumers do not know what is available. Twenty-four percent of consumers indicated they were "uncertain" about the support services available in their community, and thirty-three percent of consumers indicated they could benefit from support in figuring out what resources might be useful to them.

> *"You get intimidated when you have too much information and you don't know what to do. There should be a system where all of the resource information is centralized." (Consumer: SSLU)*

Poor Service due to Restrictive Guidelines. When services are un-coordinated, there tends to be more overlap and gaps in service, largely because of the mandate of each individual service. (Consumer Leaders; Community Meeting). Sometimes the person must go without service, sometimes wait a long time to get it, and other times experience duplication in available services.

> *"Some of our clients are double booked with support care workers and Homemakers. Many of the duties performed are the same. This overlap causes [consumer] confusion."*
> *(Community Meeting)*

> *"The individual has difficulty accessing services and often 'falls between the cracks'." (Service Provider: Community Meeting)*

A telling example of the impact of each agency having its own restrictive guidelines was recounted by several consumers. In one situation, for example, a person had to stay in bed for an extra two hours until the appropriate person came to lift her out of bed, even though a nurse had recently been there to assist with bowel and bladder routines. (Consumers: Outreach; MCSS staff; Service Provider: Outreach).

Lack of Clear Definitions Around Medical/Non-Medical Procedures. The lack of clarity of whose responsibility it is to provide certain services such as bowel and bladder routines is the result of a lack of clear definitions. Each agency makes its own decision about whether bowel and bladder procedures are personal support or a medical support and makes the resulting policy about who is allowed to do this procedure (Consumer Leaders; Community Meeting).

> *"At our place, they won't do catheter care; if there is a problem at night, like it comes out, then the person must go to the hospital emergency department to have the catheter inserted." (Consumer: SSLU)*

> *"The problem is defining what is personal care; what Homemakers do is the same as us; the difference is in interpretation. We can't provide a medical service, but what is that anyway? What if we're sued for a bowel or bladder procedure? Now it's so wishy washy. We have the same duties on paper, but in practice they differ. For example, they won't do bowels. Clarity of the guidelines is needed to help interpretation." (Service Provider)*

> *"When we have to do something that consumers would normally not do for themselves, then we might see it as nursing." (Service Provider)*

Some feel that Outreach and SSLU workers should all be well trained in bowel and bladder procedures, particularly since families are generally trained. (MCSS staff; Consumers: SSLU).

> *"For catheter training, just send them [attendants] to Lyndhurst to learn how to do the procedure because it can be a sticky wicket. The Outreach program I'm on trains staff for 3 months." (Consumer: Outreach)*

> *"If we can train families, why can't we train attendants? We would need common guidelines. The Ministry of Health should provide catheter training in projects because we can't get services. We can't go to the washroom because of time limits. We have to swallow what we're given." (Community Meeting)*

Fragmenting the Person when Cooperation Lacking. When consumers receive services in a system that is not co-ordinated or co-operative, they feel fragmented.

> *"Service providers have to learn to work together and stop being competitive. We have to integrate because if we don't, the consumer will always be fragmented." (Service Provider)*

> *"There is a lot of bureaucracy in filling out application forms. There should be some co-ordination between service providers." (Parent: Community Meeting)*

> *"If you fragment the service, you fragment the client. It is very difficult to work with VON and other agencies." (Service Provider)*

These dilemmas of fragmentation and poor co-ordination have been highlighted in recent years with the introduction of the Integrated Homemakers Program. By early 1988, approximately one-third of the Province had Integrated Homemakers. The attached chart illustrates the major components of the Integrated Homemakers Program. By the end of 1987, Integrated Homemakers was serving almost 1,000 disabled people and over 10,000 elderly people. Interestingly, MCSS officials express "surprise" that more disabled people have not been interested in the service. To date there has been little collaboration or co-ordination between the Integrated Homemakers and Outreach programs. This would require greater collaboration between the Ministries of Health and Community and Social Services.

Toward More Cooperation Among Agencies.

Most individuals and groups emphasize that there must be more co-operation in the system if people's needs are to be better met.

> *"Several agencies could provide a similar service, but people could choose. But services are very competitive. They fight over clients and dollars. We would need much more co-operation among agencies." (Consumer Leader)*

Several communities realize the impact that lack of co-operation is having on services and individuals and are attempting to work with other groups.

Integrated Homemakers Program

The Integrated Homemakers Program is designed for "frail elderly persons" and "disabled adults eighteen years and over."

The Integrated Homemakers Program (IHP) is funded under the Homemakers and Nurses Services Act, which under regulation 499, provides the following "Homemaking services."

- the care of a child or children
- meal planning, marketing, the preparation of nourishing meals, and special diets where required
- light, heavy and seasonal cleaning
- light laundry, ironing and mending of clothes
- personal care including assistance and walking, climbing or descending stairs, getting into or out of bed, eating, dressing, bathing and other matters of personal hygiene
- simple bedside care where required under the direction of the physician or nurse not including nursing services
- training and instruction in household management and care of children.

The IHP maximum is 60 hours per month. The service is available between 9 a.m. and 5 p.m. Monday to Friday.

"Our co-operation with other agencies like Homemakers and Red Cross helps; we take the responsibility for co-ordinating things; the consumer gets one person in there if we work at it." (Service Provider: Outreach)

"We are co-operating with other Toronto attendant care projects and have picked one agency to develop a relief program just for us. We hope this will bring more continuity, and we [service provider] will do the training." (Service Provider: Outreach)

"Our good relationship with other groups like the Ministry of Health, discharge at hospitals, CPA, and the MS Society all pay off in terms of getting lots of referrals and support. We don't tend to get spinal cord patients however; they seem to get referred to SSLU." (Service Provider: Outreach)

MCSS officials note that the Integrated Homemakers Program is moving toward "one-stop access" for Homemakers services, perhaps one resolution to poor co-ordination among agencies. While some people wondered if Outreach might also fit under one-stop access, most consumer leaders noted that this was problematic. The major concerns were in terms of the delivery issues which contribute to perceptions of fragmentation.

- The Integrated Homemakers Program is highly associated with elderly people and has the perception in communities that it is a program for people who are frail elderly. Consumer leaders ask whether people with physical disabilities have difficulty associating themselves with such a program?

- The Integrated Homemakers Program is actually administered by the Ministry of Community and Social Services, but through the Ministry of Health. As one MCSS person noted, "this is needlessly complicated," and this program still finds consumer direction and control rather foreign.

- The Integrated Homemakers Program is having difficulty adjusting to the fact that "the young disabled person who works may need care early in the morning and again later at night." Current guidelines simply do not allow this arrangement.

Some people also feel that the Ministry can play a co-ordinating or mediating role between consumers and service providers.

> *"A coalition for transitional living made up of service providers, wanted to incorporate and start developing homes. The consumers intervened, and with support from the Ministry, had the coalition's decision put on hold." (MCSS staff)*

> *"I get to see how programs work together and if they're not working well together I work with the agencies." (MCSS staff)*

There was also some feeling that the Ministry needs to be taking a stronger planning role, particularly in comparison with the significant amount of long range planning coming from the policy branch in the area of developmental disabilities. (MCSS staff; Service Provider; Consumer Leaders)

DISSATISFACTION WITH OUTSIDE AGENCIES

Most people indicate that they are happier with the services provided by Outreach or SSLU agencies than they are with those provided by outside agencies. The reasons given vary from individual to individual.

Arbitrary Decisions. Many people note that they are more vulnerable with outside agencies. They feel that if the agency does not approve of their lifestyle or if it decides they are simply too handicapped, it can deny service, and/or leave little alternative other than institutionalization. (Consumer Leaders)

> *"If handicapped people don't comply or conform to the rules of society, then they can get their services withdrawn." (Service Provider)*

> *"What right does an agency have to tell me what I can do and what I can't do ?" (Consumer Leader)*

Outside agencies' concern for legalities tend to increase their arbitrary decisions, and inhibits them from consulting with consumers around their needs or wishes.

> *"There appear to be more difficulties in dealing with professional agencies because they are so concerned and over protective about doing things within policy guidelines and the legal aspect of it. I've never heard a consumer be concerned about the legal aspect. I'd sooner die in my apartment on my own because of a fall than being forced into a protective institution. The consumer is willing to take the risk." (Consumer Leader)*

Rigid Scheduling. Many agencies, such as Red Cross, appear to have more rigid scheduling. For example, in most communities, they provide support in three-hour blocks, rather than in flexible one-hour blocks throughout the day. This makes people more dependent on their families or friends for support in between these blocks or leaves the person without support during other important parts of the day. (Service Provider; Consumer Leaders)

> *"One 25 year-old man, a quadriplegic, was receiving support care from 12:00 noon to 3:00 p.m. The worker got him up at noon and put him back to bed at 3:00. He was in bed until noon the next day. He had no family to offer alternative support and was eventually re-institutionalized." (Parent: Board of Service Provider)*

Quality of Staff. People are clearly happier with the quality of staff provided by Outreach and SSLU as compared to outside agency staff. Agency people are seen as being less competent and caring. (Consumers: Outreach; Consumer Leaders)

> *"An attendant from a private agency was drunk one night and brought a friend. At 2 a.m. the smoke detector went off. A cigarette had gone down the couch. I phoned the fire department. Now the superintendent knows if the alarm on the 10th floor goes off, he comes here first." (Consumer: Outreach)*

> *"Most tenants hate agency staff. If an agency staff comes now, often the person sends them away and we have to pay and then they call us to come, which we can't." (Service Provider: Outreach)*

There also seems to be some concern that agency staff do not listen as well or respect the person's opinion.

> *"The regular staff are good but the concern is with the relief staff (outside agency staff). Some listen and some don't . People who have worked in nursing homes or who are from agencies come from the school of thought where they decide what to do for you instead of asking us." (Consumer : SSLU)*

> *"She seemed to think exercises weren't very important until the physio talked to her. She was willing to take direction from a professional, but not from me who she is working for." (Consumer: Outreach)*

According to consumers, staff in outside agencies appear to be less reliable than those in Outreach agencies. Many times people have complained of being left with no service at all. (Consumers: Outreach).

> *"With Red Cross we've been left without someone several times. It was difficult when I was at work because I always had to worry about what was happening at home." (Spouse: Outreach Consumer)*

Unfair Wage Discrepancies. Many people, particularly service providers, resent the large discrepancies that exist between their own staff's wages and what is paid to outside agencies. They feel it is distorting the real cost of attendant services. They also feel this makes it difficult to attract and keep good staff, many of whom have similar job descriptions to other agency staff.

> *"We only use these agencies for an emergency. They charge us $12.50 an hour and must be paid for a minimum of 4 hours, even if we only use them for 1/2 an hour. They pay their worker $7 lets say for the hour they worked so look at the profit. Of course we would rather have our own attendants, it's a rip-off." (Service Provider: Outreach)*

> *"You can go to an old folks home and get better salaries. If they would raise the salaries, attendants would stay." (Attendant: Community Meeting)*

On the other hand, there is some hope that these higher salaries will help to increase the wages of Outreach and SSLU staff.

> *"Recently there have been higher settlements with other service providers which will impact on the scale across the province. The attendant care system is being recognized as a growing industry, it is necessary, it is not going away, and the monetary remuneration must reflect this." (Consumer: SSLU)*

SUMMARY AND RECOMMENDATIONS

The findings in this Chapter will be briefly summarized and related to possible policy and structural changes which need to occur at several levels.

This Chapter focuses on the many problems that result when services are fragmented and un-coordinated. The problems of poor co-ordination and fragmentation are not new findings in human services. Studies in mental health and physical disabilities have emphasized these problems for more than a decade (Church, 1985; Clague et. al., 1984; Flynn & Nitsch, 1980). There is no question that as human service systems have become more complex, these dilemmas have increased.

The data from this Review show that most people receive their support from at least two and usually three different agencies; in the process of receiving their support from multiple caregivers, consumers experience much personal frustration and fragmentation. Many feel that the solution to this fragmentation lies in reducing the number of caregivers and agencies in their lives. At the same time, people clearly want the option to decide where their support care will come from, how many agencies will be involved, and whether only one or several attendants will actually provide the support. In support of this consumer perspective, there is some evidence which suggests that "focusing on the individual" is a key notion to improved co-ordination (NIMR, 1982; Lord, 1985; Richler, 1981). A consumer directed or self managed approach will help create a consumer driven, as opposed to an agency driven system.

Therefore, the first recommendation, dealing with this element of consumer choice, is:

32. **That individual consumers be given the choice of deciding which, if any, agencies they want to involve in providing their support; if they so choose, consumers should have the option of selecting individual funding and arranging for their own**

support, with or without the involvement of an agency.

For individuals who choose to receive their support primarily from one person, and if they want Outreach to be the lead agency, the service will need to be much more flexible in order to respond to personal needs and requests. There will need to be a careful matching of attendant to consumer so that a good working relationship and a sense of commitment is achieved. In this situation, Outreach attendants would also require an expanded mandate so that they could assist with independent living in the fullest sense of the word. This would entail providing personal care, including bowel, bladder, and catheterization; homemaking; support with shopping, banking and other outings. For a more complete discussion of this expanded role, refer to Chapter 7 "Restrictive Policies".

What can be concluded, is that not only does the role of the attendant require expanding in order to respond more fully to the broader needs of the person (discussed in depth in Chapters 3 and 7), but as well to provide a solution to the fragmentation experienced by individuals who use several agencies for support. Therefore, it is recommended:

33. That the role of the Outreach attendant care worker be expanded to include not only personal care, but also homemaking and routines such as taking medication and/or needles, catheterization, and bowel and bladder; and that these latter routines be clearly defined as personal care and included in the role of attendant care workers for consumers who so choose.

34. That for those people who wish to continue receiving their support from multiple agencies, that the current approach be maintained as an alternative; for example, some individuals would like to maintain the option of having someone with a medical background perform specific personal care functions such as injections or catheterization.

It is recognized that any changes involving more than one ministry are most difficult to achieve. However, because of the overwhelming agreement amongst consumers and service providers in this Review, there is no alternative but to suggest some policy options that deal directly with the problem of multiple agencies and overlapping Ministries. The two most useful policy options would involve:

- Amalgamating Outreach and the portion of Integrated Homemakers Program (IHP) that services people with physical disabilities (approximately 10 percent of their clients) into one lead organization providing the full range of independent living assistance. Dollars would have to be re-allocated accordingly from IHP to Outreach.

- Establishing a system whereby the IHP could transfer funds on an individual basis to the Outreach program to cover the costs of one attendant providing total homemaking and personal care support, at the request of the individual.

In order for these policy options to be possible, service co-ordination will need to be mandated. This call for improved co-operation between existing agencies is neither original, nor does it seem to work on a voluntary basis (Myers, 1978). Perhaps the only way to achieve effective co-ordination between services is to develop a shared sense of working towards a common goal, and then mandate co-ordination at a policy level.

> "Every agency has a vested interest in one or more programs... Each agency will continue to do its own thing unless it is forced into a co-ordinated, co-operative effort to plan and deliver its resources to the appropriate place at the appropriate time " (Myers, 1978, p.21)

We noted in several communities, that agencies are attempting to voluntarily co-operate with each other. This form of voluntary co-operation must be respected and supported as an important local community initiative; in a few sites, this co-operative interaction was an essential component of the whole culture of that community. However, this was not true for every place that we visited, especially in the larger cities. At one level, it is highly questionable if agencies and organizations can voluntarily share information, plan together, and make decisions that are based on the best interests of the clients and the community (Lord, 1985).

It is therefore recommended:

35. That the Ministry of Community and Social Services initiate discussions with other Ministries, particularly

Health, to attempt to increase their understanding of the serious negative impact on the lives of consumers who must receive services in a system that lacks co-ordination; and that the Ministry examine in detail ways to implement a policy option to maximize individual service co-ordination.

36. **That the comprehensive long range Plan include the concept of a lead agency as a way of providing greater co-ordination at the individual level.**

This inter-ministerial co-operation would provide the opportunity for both Ministries to re-assess their whole approach to people with physical disabilities and to improve the piecemeal approach that has been taken to providing services. More specifically, it would also force a re-evaluation of the view that Outreach is simply a supplementary program to the Integrated Homemakers Program.

Chapter 9

STAFFING ISSUES

While policy development and program planning are the essential components for service delivery, staff are the most visible aspect of any service. There are several factors that contribute to the quality of attendant care - staff training, attitudes, satisfaction and commitment to the job. These factors all have a huge impact on consumer satisfaction.

In analyzing the qualitative data on staffing issues, it was quickly apparent that consumers are generally pleased with the staff in both the SSLU and Outreach programs. (Consumers: SSLU & Outreach; Consumer Leaders).

> *"There should be more projects with the nice staff we have here." (Consumer: SSLU)*
>
> *"I think we're all one big happy family. It doesn't matter if support care changes from time to time, there's a certain bonding you get with certain staff." (Consumer: SSLU)*
>
> *"They're there when I need them. Always ready to help. If I was living at home during the day I'd be alone." (Consumer: SSLU)*

The findings from the quantitative survey substantiate the learnings from the interviews, and clearly demonstrate the overall level of satisfaction with staff (Table 11 depicts these findings). It is interesting to point out two specific findings from this data. First, the two areas where consumers have the least satisfaction are "attendants' orientation to independent living" and the "turnover of staff."

Second, Outreach consumers are much positive about staff's "willingness to do tasks most essential to me". This is a puzzling finding in light of consumers' concerns about attendants not performing bowel and bladder routines. People may have been referring to just the tasks that are outlined in a service contract. What we do not know is the number of

Outreach respondents who require assistance with bowel and bladder routines.

Table 11

Consumer Satisfaction With Attendants

My attendants are:	SSLU agree (%)	Outreach agree (%)
1. Personally suitable for this job	83	89
2. Well trained for the tasks required	78	78
3. Well oriented to independent living	63	63
4. Available when required	83	77
5. Willing to do most tasks essential to me	78	92
6. Here for a long time (Low turnover)	60	66

Despite the relatively high level of satisfaction expressed in the survey, in the personal interviews some important staffing issues emerged. Running like a thread through every issue is, once again, the recurrent theme of consumer control and independence. The findings on staffing issues are:

1. ***People have various needs that they hope to have met through their relationship with their attendant; and a sense of control and respect are essential ingredients for a good consumer/staff relationship.***

2. ***People believe that staff training could be improved, but there are sharply divergent opinions as to how this could be accomplished.***

3. ***Staff turnover affects the quality of service and is a source of frustration for both consumers and service providers.***

4. ***People want the option to choose whether or not they are involved in the hiring and firing of their own staff.***

5. ***There is a constant tension between service providers who are trying to schedule to meet everyone's needs, and consumers who want more individualized flexible scheduling.***

CONSUMER/STAFF RELATIONSHIPS

The relationship which develops between individuals and their attendants often varies depending upon people's other needs. For example, the need for friendship is a top priority for some consumers, whereas other individuals clearly distinguish between the role of an attendant and the role of a friend. In many cases, the nature of the relationship comes down to a question of who has control, the attendant or the consumer.

Who Has Control?

A number of service providers are very attuned to the consumer's need for independence and control in their lives. (Consumer: Outreach & SSLU's; Service Providers; MCSS staff). However, these providers also admit there is an ongoing tension between staff and consumers around the issue of who ultimately has control. (Service Providers: SSLU; MCSS staff)

> *"There's always a quiet struggle between staff and tenants ... always negotiating going on of how complete the control is going to be." (Service Provider: SSLU)*

> *"We're in a power position and we have to be very careful of that...Do we make decisions for the client based on what would conform to what we want done in our program to help things run smoothly?" (Service Provider)*

> *"This becomes complicated with attendants who have trouble taking a back seat to the person with whom they are working. We need to be upgrading the quality of the attendant care worker, so they can read their individual better." (MCSS staff)*

Despite the fact that many service providers recognize that the attendant should respect an individual's wishes, some consumers (Consumers: SSLU; Consumer Leaders) cite examples showing how this does not always happen. One woman, for example, noted the reaction of staff in an SSLU project when they discovered she was sexually active. A staff member questioned her contraceptive practices and admitted to listening outside her door.

> *"I thought the staff were really taking over - telling you how to live your own life." (Consumer: SSLU)*

Several other consumers expressed concern about the fact that staff seem to resent people's input into how their personal support is managed.

> *"They think I like to be bossy. I was just trying to save steps by giving a proper direction...I'm sure a lot of staff think you're finicky but they don't understand your condition." (Consumer: SSLU)*

> *"Outside of the project, yes I have control, inside no, I have no control. There is one staff for six of us. There might be one person who wants to help you with independence. Suppose I want to get my hair washed every second day (which is my top priority) and the staff who is on doesn't like washing hair. Either they do such a bad job or they don't do it. They take control (of you) when they decide what they like to do." (Consumer: SSLU)*

When a consumer feels a lack of control with the attendant, real personality conflicts can happen. (Consumer: SSLU; Service Provider)

> *"There are some people you literally can't stand. It's very hard to talk to someone you don't like...These things cause me the most stress. It's hard to deal with. For my physical and mental health it's important to keep stress down. " (Consumer: SSLU)*

For some people, a lack of control in their staffing relationship translates into a fear of, or actual, retaliation. (Consumers: SSLU & Outreach; Consumer Leaders). The retaliation could be as subtle as your attendant not doing things the way they know you like things done, or as extreme as the threat of loss of service for someone who complains (Consumers: SSLU). It is clear that both programs have to be vigilant in ensuring that consumers maintain realistic control in their situations.

A number of Outreach and SSLU service providers feel that consumers do not always have the capacity and/or the willingness to take charge and make the decisions in their lives. This is largely believed to be due to the fact that many people do not know how to make personal decisions, especially if they have spent a lot of time in institutional or protective family settings. One Outreach service provider states that some individuals with disabilities prefer others to direct their lives for them; another service provider claims some people are simply non-accepting of themselves or the services offered - they see themselves as victims.

> *"People say they want to control their lives, but they're always coming to me saying they can't handle it...They have to make up their own minds that they are going to accomplish what they set out to accomplish." (Service Provider: SSLU)*

In contrast to this argument, several consumers who are capable of directing their own staff indicate the significant role staff play in supporting or undermining an individual's level of control. One consumer leader points out that many agencies seem to operate on the assumption that people are incapable of directing their own care.

> *"This (assumption) rather ironically, addresses the needs of the client who cannot self direct or organize himself, but impacts extremely negatively on the client who wishes to control his own daily affairs. The whole intent of the program is undermined in such a situation and becomes nothing more than the institution moved into the home!" (Consumer Leader)*

It was suggested by some consumers and service providers (Community Meeting: SSLU Service Providers; Consumer Leaders) that consumers need workshops and educational sessions on how to direct their own care and relate constructively with staff and other tenants. One of the sites that we visited offers this form of training through an Independent Living Centre; this seems like a very appropriate setting for dealing with the issues around consumer control and staffing.

A Respect for Privacy

It appears a person's privacy is more easily violated in the SSLU projects than in Outreach. People complain about a breach in confidentiality because staff sit in the staff lounge and discuss the tenants (Consumer Leaders; Consumers). People also dislike the fact that staff sometimes talk about other tenants in front of them (Consumers: SSLU).

> *"Two staff would come into our room and talk about another tenant while they were doing personal care. They'd talk as if we weren't there." (Consumer: SSLU)*

Consumers from one project also claim SSLU staff tend to come in and out of the units at will. In another SSLU project, the tenants are allowed no overnight guests; they can have guests of the opposite sex in their rooms as long as they leave the door open. (Consumers: SSLU)

Although confidentiality is not as great a concern with the Outreach program because staff do not have the opportunity to converse regularly, there is the problem of having more than one care-giver tend to your intimate and personal needs.

> *"It's very difficult for my son. He is shy and has a hard time with so many people coming in and out of the house." (Consumer: Outreach)*

This lack of privacy with multiple attendants is compounded by high staff turnover. This will be discussed in the next section.

STAFF TURNOVER AND THE IMPACT ON QUALITY OF SERVICE

High staff turnover, a shortage of staff, and staff unreliability are all inter-related problems that affect the quality of the service provided and have a substantial impact on an individuls's life.

The Nature of the Problem

Staff turnover is a reality for both the SSLU and Outreach programs, although the Outreach program appears to be especially plagued with this problem. An Outreach service provider notes that highly qualified people tend to use Outreach as a stepping stone to better paying jobs. Another service provider points out that people tend to use Outreach as a source of quick money. Over this past Christmas she hired 25 new staff and only five were remaining at the end of January. A third Outreach service provider mades the following comment:

> *"Now there is only one person who has had the same attendant for a long time. There just aren't that many people who will stay. It's not a good career job." (Service Provider: Outreach)*

Obviously, rapid staff turnover will affect the amount of training staff receive. One service provider noted, "sometimes you need the staff so fast you do not have time to train them." (Consumer Leader; Service Provider). Similarly, a teacher who offers an attendant care course at a community college remarks:

> *"Agencies don't like to invest in training for attendants because they tend to move on to better paying, full-time jobs a short time after they're trained. " (Community Meeting)*

The result of high staff turnover can be a temporary or permanent staff shortage. In the Outreach programs, this results in long waiting lists; in the SSLU programs, this can result in rigid scheduling and group programming that stands a limited chance of meeting everyone's individual needs, and of facilitating personal control. Program directors of both Outreach and SSLU projects point out their difficulties in providing enough service, especially during peak times such as meal and bed times.

> *"The shortage of attendants is quite severe, and although we provide service or facilitate the client to arrange their own service, attendants are always hard to find." (Service Provider)*

In Outreach, a shortage of staff can also mean limited services for the weekend. Consumers at a few sites complain they are unable to obtain any attendant care on the weekend.

The Impact of Staff Turnover on Consumers

For consumers, staff turnover has quite an impact on their dignity, their privacy and their sense of control in their lives. (Consumers: SSLU & Outreach; Service Providers: Outreach; Community Meetings)

> *"You get aggravated when you are used to having someone coming in doing bowel care which is very personal and they keep changing staff on you. My regular staff knows my routine, my moods and when to leave me alone. It isn't helpful to keep changing staff." (Consumer: Outreach)*

> *"Staff are constantly changing. There is high staff turnover. This impacts on the person's sense of control, dignity, privacy, self esteem, self image. It can be humiliating if the first time you meet an attendant is when he comes to get you up in the morning and you are lying there naked. " (Community Meeting)*

There is also the aggravation of constantly having to train new staff.

> *"There is a sense of being a guinea pig too... new staff train with the same consumers for things like intermittent catheterization and bladder irrigation. Once the attendant is trained, a V.O.N. comes in and observes, then certifies. It becomes very irritating for the individual and many have completely refused to do it any more." (Community Meeting)*

As noted earlier, high staff turnover can lead to a temporary or chronic situation of staff shortages. In one project, a lack of staff means some people, in order to get to work on time, get up at 3:00 or 4:00 in the morning to do their bowel routines (Consumer Leader). Consumers acknowledge the staffing shortage means they have to compromise in getting their needs met. (Consumers: SSLU)

> *"There is a staff shortage. You always have to "trade-off" one activity for another. If I have an attendant for one-half hour and I need physio and a shower I have to trade one off for the other." (Consumer: SSLU)*

> *"You need to be very flexible about what type of things you want done. You can only get the very essentials done and there are no extras - especially related to housekeeping. We get our place cleaned every two weeks. In winter the floors are dirty (tracking in mud and ice) and you can't have it cleaned unless it is your scheduled day." (Consumer: SSLU)*

> *"When I do not have a backup and the attendant does not come, it is real scarey." (Consumer: Outreach)*

Several consumers (Outreach) recommend there should be a backup pool of attendants, so consumers are never left in the lurch.

The Reasons for Staff Turnover

It is widely acknowledged by consumers and service providers that the most obvious reasons for staff turnover are poor pay, a lack of benefits, and a dissatisfaction with the hours. (Community Meetings; Consumers: SSLU & Outreach; Service Providers: SSLU & Outreach). Interestingly, the survey data show that, while 17 percent of attendants are not satisfied with the hours they work , 41 percent are not satisfied with rate of pay.

> *"It's like a chicken and egg. You want good attendants...but what good attendant would work for nothing?" (Community Meeting)*

> *"They are paid $6.67 probation, $7.30 at 6 months and $7.80 at 18 months. Since the pay is so low, it is hard to attract strong people. The pay and nature of the job is such that most people would not want to make a career out of it...Our staff at least want a Metro pass since that is how they get around. We cover this by paying them a half-hour salary, how else can we do it. If they have four stops, getting to each one is our time really, not theirs." (Service Provider: Outreach)*

We have to question if the low wage scale for attendants is reflective of the fact that society does not place a high value on non-medical, support services. Child care workers, for example, suffer from the same poor pay. For people with disabilities, the value of independent living assistance cannot be under-estimated; attendants play an essential role in people's lives. Unfortunately, societal attitudes seem to perpetuate the myth that attendants are underpaid nurses, adult babysitters, or cheap domestic help. One project director analyzed the situation in the following manner:

> *"We need more money for staff. There is a problem with attitudes. People are making the assumption that attendants are doing domestic work and the salaries are targeted at that. People in government don't mind that there is a high turnover rate because of their perception of the roles (for attendants)." (Service Provider: SSLU)*

Not only is the job of an attendant low paying, difficult, and misunderstood, but there is little potential for career advancement.

> *"It's becoming increasingly difficult to attract people and then to keep them. It's an extremely difficult job. You have to be a special person...Young people like the job, but if they'd like to advance where do they go?" (Service Provider: SSLU)*

Attendants obviously need their own support systems. While this may be possible for SSLU workers, Outreach attendants are more likely to be isolated from each other and without a strong support network. (Service Provider: Outreach).

STAFF TRAINING

From the analysis of data, the whole issue of staff training proves to be quite contentious. The survey findings indicate that 78 percent of the consumer respondents feel their attendants are "well trained for the tasks required," and 87.5 percent of the attendants are either "satisfied" or "very satisfied" with the training they received. Despite these quantitative findings, our qualitative interviews demonstrate that a number of service providers and consumers hold very strong views on current methods of staff training, and on the quality of individuals who are becoming attendants. People express sharply divergent opinions on how attendant training could be improved.

Quality of Attendants and Current Staff Training

It would appear the bulk of the attendant training is done by the individual agencies. Within each agency, the extent to which the training is conducted by other staff, by professionals, or by the consumers themselves depends upon the interpretation or management practices of the program directors. Below are a variety of perceptions and approaches of four different service providers.

> *"We recognize training could be a weak point in developing an attendant care program. It's been an omission because everyone assumes everyone can direct their own care. Many people we see do not know how to handle life skill situations, but it is not in our proviso to do this training as care-givers." (Service Provider: SSLU)*

> *"If the person has had lots of previous training they are given five orientation shifts...The first day they are given a crash*

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> *"If the person has had lots of previous training they are given five orientation shifts...The first day they are given a crash*

> *course on everything attendant care does. Then they buddy up with an experienced staff, they view a twelve minute film on back-care, and they have ongoing training with staff and tenants." (Service Provider: SSLU)*

> *"As part of the training, we tell staff that it's the person's home and they're the boss...At the same time people with disabilities have to be trained themselves to be able to manage their attendant care." (Service Provider:SSLU)*

> *"Staff are hired with no experience in attendant care and sometimes no education in human services, but tenants train staff...It is their right and their responsibility to train and direct their care." (Service Provider: SSLU)*

A number of consumers (consumers: SSLU, & Outreach; Consumer Leaders) feel that staff are inadequately trained by the agencies. They complain the new staff are sometimes into the job before they are given any background training. (Consumers: Outreach & SSLU).

> *"Right now they're hiring them first and training them by showing videos two months later-it doesn't make a lot of sense." (Consumer: Outreach)*

> *"They take someone around for three days and have the new staff watch them. Basically its useless as the new staff don't watch closely." (Consumer: SSLU)*

Some consumers (SSLU & Outreach) claim they do not have control over which attendant is training the new staff member, and therefore can only hope the trainer really understands their particular needs. Unfortunately, sloppy habits could get passed on from one attendant to another with potentially disasterous effects for the consumer. One consumer gives the example of an attendant who fails to wash his hands between doing the bowel routine and the bladder routine. Carelessness such as this could lead to a bladder infection that could seriously harm the individual. (Consumers: Outreach & SSLU).

People also talk about the quality of staff that are being hired, and the attitudes that they bring to their job. (Consumer Leaders; Consumers: SSLU & Outreach; Community Meeting; Service Providers: SSLU & Outreach).

"We hire people who are not appreciative of the Independent Living movement (ie. R.N.A.'s) or people who are new to the culture. They want to control, or want to form a mother/daughter relationship (with consumer). We don't find out until usually after the fact." (Service Provider: Outreach)

"A lot of people are trained for hospital and institutional work; when they show up in a white uniform, we know." (Service Provider: Outreach)

What Training Do Attendants Want?

In the survey, attendants were asked what training they feel they would like to receive. The findings are highlighted in Table 12.

It is interesting that in 4 of the 6 categories, Outreach attendants indicate a stronger desire for training than SSLU workers. Two-thirds of the Outreach attendants want training in "current values and trends in the disability field" and one-half in "facts about different disabilities". It does appear that Outreach attendants are reflecting the isolation which it is possible to feel as an attendant working with one person or travelling to a variety of people's homes.

These are important findings which could provide guidance to Outreach and SSLU agencies in their planning for attendant training. SSLU attendant training needs to reflect the attendants' desire for improved communication and ways to encourage consumers to direct the attendant. Many attendants from both programs also indicate they desire training about the emotional needs of disabled persons and their families.

While these data from attendants are very relevant, they must also be examined in light of *how* this training should be carried out. We now look to consumers and service providers to help us with this issue.

How Should Attendants be Trained?

There are divergent opinions on how attendants should be trained, ranging from some consumers and service providers who want more standardized professional training for attendants, to other consumers and providers who believe that training should primarily be in the hands of the consumer.

Table 12

Training Desired By Attendants

Training Wanted	SSLU (%)	Outreach (%)
1. Current trends and values in disability field	24	67
2. Facts about different disabilities	18	53
3. Emotional needs of disabled	33	47
4. Personal care approaches	11	32
5. Communication skills and methods	31	10
6. Ways to encourage consumer to direct the attendant	27	22

Consumers who support standardized training for attendants have a variety of reasons for doing so. (Consumers: SSLU & Outreach; Community Meeting). At a basic level, people believe it is logical to develop a consistent format for training.

> *"They should have a course subsidized by the government that attendant care workers have to take before they can work in the field. Two days training is not enough." (Consumer: SSLU)*

> *"If they (attendants) had a certificate they would feel that they should be respected. The training should include an internship so that they could appreciate the job that they are doing." (Consumer: Outreach)*

A few people also feel that a more professional approach in attendant care training would give them greater confidence in their attendant.

Interestingly, the emphasis from these consumers and providers is on training with a medical focus. (Consumers: SSLU; Family Member: Community Meeting).

> *"The training of attendants should not be done by the individual SSLU's. I have often been called into units (SSLU) where consumers have been injured by attendants who don't know proper transfer techniques. Attendants should be trained by professionals. If there was a core program for training it would be better." (Physiotherapist and wife of consumer)*

> *"It relieves me to know that she (the attendant) has a nursing background and knows about my disease (MS), so I have confidence in her... I would like to see a good training program - not necessarily medical, but a good program that teaches people to spot medical problems when they arise." (Consumer: SSLU)*

Not everyone shares the view that attendants should have a more medicalized training. Several consumers and consumer leaders protested that the last thing they need is someone with a medical background providing care. As one consumer notes, the care-giver would probably be "locked into her training and attitude." Another emphasizes;

> *"We are disabled people not sick people...I've hired people for support care. The two most important aspects are the personality and the attitude of the individual - they can be trained to help me." (Consumer Leader)*

According to one program director, there are too many attendants with nursing backgrounds who concentrate on physical care and not on communication or inter-personal skills. Her solution to this problem has been to work with a community college to establish a one-year training program for attendants. It is slated to start in September 1988.

> *"Its focus is to train attendants to work with physically disabled people who have the potential to direct their own care, but need assistance." (Service Provider : Outreach)*

The Ontario Federation for the Cerebral Palsied, in its submission to this Review, also recommends:

that the Ministry develop provincial standards for staff qualifications, through encouragement and support of college level training for support service staff across the province.

The notion of a community college program for attendants is greeted with mixed reviews from consumers and service providers alike. (Consumer Leaders; Community Meeting; MCSS staff; Service Provider). One program director is concerned that the college training would not meet their organization's current standards of training; it could also prove to be less cost efficient than doing your own in-house training. Several other service providers feel that a college training would undoubtedly take control away from the consumer. (MCSS staff; Service Provider)

> *"You need to develop a working relationship between the consumer and the provider. You really can't teach that in school." (MCSS)*

Maintaining consumer control in the training of attendants is the key concern for many consumers. (Consumer Leader; Community Meetings; Service Providers; Consumers: SSLU & Outreach). It is believed that any form of accreditation could introduce the concept of professionalization. This in turn would undermine an individual's ability to direct his or her own care. The Ontario Advisory Council for Disabled Persons (1988) raises extensive concerns about professionalization of support workers and identifies the limits of certification. A consumer leader reflects this perspective most clearly:

> *"One of the dilemmas for disabled persons requiring attendant help is that often, along with higher education and increased "professionalism", comes a dominance that is difficult to deal with. Persons who have lived with their disabilities a long time are often more "expert" than anyone else in knowing their own needs and in self-directing their care, in the same way that any able-bodied person organizes to ensure that personal physical needs are met as he prefers... Any educational program, in this area, unless carefully designed, raises the danger that disabled persons, the recipients of attendant care services, will come to be percieved as "patients" with all the inadequacy and dependency therein implied. " (Consumer Leader)*

Time and time again, vocal consumers assert their right to do their own training. In Table 13, the survey results show that 57.6 percent of the

Outreach consumers and 66 percent of SSLU consumers indicate that it would be "desirable" or "essential" to have more control in the training of their own staff.

> *"I train my own attendant; while it is important they have some background, most of the training can be done by the consumer." (Consumer: Outreach)*

Table 13

Consumer Control in Staff Training

	Not Necessary (%)	Desirable (%)	Essential (%)	Totals N	Totals %
Outreach	42.4	39.4	18.2	33	100
SSLU	34	40	26	47	100

Consumer Control in Supervising Staff

	Not Necessary (%)	Desirable (%)	Essential (%)	Totals N	Totals %
Outreach	45.5	45.5	9.1	33	100
SSLU	37.3	39.2	23.5	51	100

> *"The one I have right now won't be trained - she insists on doing things her way. It's a little bit annoying, she comes into my home but won't do things my way." (Parent: Community Meeting)*

There was a recognition that if consumers are to be supported in their desire to direct their own care, it will require a shift in the current thinking. Rather than constantly focusing on attendant training, we should be teaching individuals how to be self-directing. (Consumer: Leader; Community

Meeting; Service Provider). We mentioned earlier that Independent Living Centres can provide a valuable function in consumer education.

While there is no clear solution to the question of how attendants should be trained, the need for options is apparent. Some consumers would prefer more professionalized training, other individuals wish to direct their training totally, and still other people may be temporarily or permanently incapable of directing their own care. An approach is needed which maintains the integrity of consumer control within a flexible model. As one MCSS staff person explained it:

> *"There is a need for flexibility throughout the entire system. Any system developed needs to respect the wishes of the consumer who wants to be totally involved, somewhat involved, and not involved in their own care. We need an appropriate mechanism for delivery of this continuum." (MCSS Staff)*

HIRING AND FIRING OF STAFF

The survey indicates that a clear majority of SSLU consumers (68 percent) and Outreach consumers (67 percent) want more input into the process of hiring their attendants. This ties into the theme of individual control that has run so persistently throughout all of these staffing issues. And once again, we have to appreciate that not every person with a disability wishes to assume the full responsibility for hiring their own attendant. People want options.

A number of people who were interviewed also believe individuals should have more input into the hiring and firing of their attendants (MCSS; Service Provider: Outreach; Consumers: Outreach & SSLU Waiting List, SSLU, Outreach; Community Meetings). They see this as a natural prerequisite to developing a clear, solid relationship between the individual and attendant. With the consumer directly responsible for hiring and paying their own attendant, any ambiguity concerning who is in charge would be alleviated. It is hoped that this in turn would lead to better reliability and quality of service.

> *"Clients need to take a direct role in recruiting, interviewing, training and scheduling directly with their attendants if their relationship with their attendants is going to develop. This allows for the growth of commitment, responsibility and mutual*

> *respect which, in return, helps to promote longevity of employment as well as more positive working relationships. Some clients might need or want assistance in developing these self-directing skills. A tailor made course of workshops in human relations or psychology might be of value." (Outreach Consumer)*

> *"If a person could hire their own attendant they would have one staff to work with all the time. They could develop an employee-employer relationship which would be a better working relationship. Staff would get more sense of accomplishment. They would see the person as a whole range of living, not just performing routine tasks ie. toileting." (Community Meeting)*

Some agencies encourage people to be involved in the hiring and firing of their attendants. (Service Providers: SSLU and Outreach). Among people that are interested in this issue, it is believed that an independent living allowance is the only way to ensure consumers absolute freedom in staffing. (Community Meeting; MCSS; Consumer Leaders; Consumers: Outreach) This option is explored in detail in Chapter 10.

> *"Right now the dollars go into an agency and people are grouped together. Ideally everyone should get their own care aid." (Service Provider)*

Options in Hiring and Firing

Not everyone wants to be directly responsible for hiring their own attendant. While some people emphasize the need for consumer training in this area (Consumer Leader, Service Providers), it should also be recognized that people see advantages in having the agency act as a broker and undertake the initial recruiting and screening of attendants. (Consumers: Outreach).

> *"I like the fact that the Outreach co-ordinator will interview our attendants if we put an ad in the paper. She is so good at matching personalities that I would never doubt her judgement to find me the right person." (Consumers: Outreach)*

> *"There is a need for a common pool of workers who have been screened and trained especially when some disabled people are*

> *unable to identify some of those potential workers." (Consumer: Outreach)*

One organization currently providing a range of support services, envisions a much cleaner relationship with individuals if they could act as the broker between an employee and their employer, rather than acting (as they do now) as service providers controlling attendant hiring, training, and firing. (Service Provider). Several Outreach agencies that were reviewed make an attempt to assist the person in choosing and hiring their own attendant. As one MCSS representative said:

> *"We need to give consideration to how to support individuals in controlling their own attendant care. The type of program that one organization provides is close to a broker model. It causes difficulties for some and it's a blessing for others. Experiences show the advantages and disadvantages of the system and who it can serve." (MCSS staff)*

The inability to direct one's own care is an obvious limitation to hiring and firing attendants and reinforces the need for options. However, as discussed earlier in this chapter, another limitation may be the chronic shortage of available staff. This poses problems for consumers who wish to hire and fire their own attendants. (Community Meeting; Consumers: Waiting List; Community Meeting).

> *"I wouldn't mind having control of payment of attendants, but there've been a number of times when I haven't been able to get an attendant - then it's been nice to be able to turn to a company where I can more easily find attendants." (Community Meeting)*

> *"The shortage of attendants is quite severe and although we provide service or facilitate the client to arrange their own service, attendants are always hard to find." (Service Provider: Outreach)*

Perhaps if people are supported in hiring their own attendants, support could turn into a less formal arrangement, with neighbours helping neighbours. This already exists, or is a potential in some rural communities. (MCSS staff; Service Provider; Consumer Leader).

> *"...such as a young mother next door dropping in for an hour or two a day or a high school student on his way to school. Persons*

> *who provide attendant help on this kind of part-time casual basis work out well and... they relate to only one or two clients with a greater commitment, sense of personal responsibility and longevity. I, for example have had the same students for two and three years now. I did the recruiting, interviewing and training. Any scheduling changes are negotiated directly between the attendant and myself, and this allows accommodation and flexibility in the schedules of both myself and my attendants as needed. The administrator only keeps the books and pays the attendant." (Consumer Leader)*

There is some research which indicates that attendant satisfaction is partially related to being responsible for only one disabled person for less than 25 hours each week (Stelmack,1981).

SCHEDULING

The results from the survey show that 59 percent of SSLU consumers and 55 percent of Outreach consumers would like more control over the process of scheduling people who provide their support. Among the people interviewed, there is a general acknowledgement that consumers tend to structure their life around the available hours of service rather than the service accommodating their lifestyle. At the same time, service providers find it is a struggle to produce a flexible schedule that meets everyone's demands.

A Lack of Flexibility

Many people talk about the problem of lack of flexibility around hours. (Consumers: Outreach; Consumer leaders) Having to schedule every activity removes all spontaneity in life - people have lost the ability just to be able to go out for a walk (Consumer Leader; Consumer: SSLU).

> *"If I could have more flexibility, like choosing my bed time, then I would be able to have more friends. This would be my dream. If I could have just this, my social life would pick up." (Consumer: Outreach)*

> *"I fit around the hours. It would be nice if I could call someone to say "Tonight I'd like to see my brother!" The program is rigid in that respect. It would cost more money for flexibility.*

> *I'd like to be on the road earlier to work, but the program only commences at a certain time. There is a direct correlation between the amount of dependence and rigidity (in the hours)." (Consumer: SSLU)*

> *"Booking is a problem. If I am booked for going to bed at 10:00 pm yet realized that tonight I have to study I would either have to go to bed at 10:00 pm and not study or wait until 1:00 am because that is the next available time to put someone to bed." (Consumer: SSLU)*

Reasons for Limited Flexibility in Scheduling. Generally, service providers and government officials feel it would be expensive to increase the amount of available service in order to provide greater flexibility for individuals.

> *"There is a fairly high administrative cost to Outreach, especially when people are scheduling hours for small amounts of time. The flexible hours certainly benefits the consumer, but it is very difficult for scheduling and administration." (MCSS staff)*

> *"The guidelines intend Outreach to not be restrictive in services to clients. However, the community must respond to what is practical, like scheduling difficulties." (MCSS staff)*

A program director observes that they make a real attempt to be sensitive to everybody's different needs. When the tenant first arrives, she/he discuss with staff the times preferred for different routines. While people frequently change their bookings, they have to be prepared for the fact that if they go out and come back later, they may have to wait to be put to bed. What seems to be needed is a good system for notifying project participants that someone has cancelled their regular booking and that time slot is now available for others.

SUMMARY AND RECOMMENDATIONS

This chapter on staffing delves into a number of key issues which have important implications for future policy decisions.

First, the staff/consumer relationship has a significant impact on a person's degree of control in his or her life. Much of the tension that can develop between an individual and an attendant is related to: (i) the extent to which an individual is capable of, or is interested in directing one's own care; and (ii) the extent to which the staff person is supportive of the individual's right to be the authority on his or her own care.

In their discussion paper on independent living, the Ontario Advisory Council (1988) grapples with the complex question of how to identify people's abilities to direct their own care. They identify three varying levels of ability:

- those who can direct their own assistance.
- those who with the development of their skills can direct their own assistance.
- those who, for whatever reason, are unable to direct their own assistance.

These three levels are very helpful as a clear portrayal of the variations in people's abilities to direct their own support. However, service planners need to guard against using these levels to develop categories. Rather than promoting a flexible attitude towards people's individual needs, categorization encourages a rigid approach to service delivery. Instead of "boxing" people, we would suggest that independent living assistance be based on the premise that consumers would like to direct their own care even though they may require some degree of assistance in order to do this. With this assumption as a starting point, people are not pre-classified, and attendants will be more likely to understand that their role is one of taking directions, not giving directions.

It comes down to a fundamental respect for the consumer. If the respect is not there at the outset, then the stage is set for conflict over the issue of who has control. In the situations where the individual appears to need some assistance in directing his or her own care, supports can be developed accordingly. (For further discussion of this point, refer to the recommendations developed in Chapter 7).

Therefore, it is recommended:

37. That providers of support services formally acknowledge that their primary goal is to respect the right of the individual to direct his or her own care and to provide support to individuals who require assistance in learning how to direct their own support.

Second, consumers are experiencing high staff turnover, staffing shortages, and in some cases, staff unreliability. All of these factors take their toll on people's dignity, privacy, and energy. It reduces individuals' ability to predict their day if they do not know if and when their attendant will come. Consistency is imperative for most people in order to plan their lives. Furthermore, if staff do not turn up, consumers can be left in very vulnerable circumstances.

A partial solution to these problems is to increase staff wages, and to pay for benefits and mileage. This would certainly help to reduce some of the current discontent with the attendant's job. As already noted, the low pay scale for attendants suggests that we place very little value on the work that they do, and yet the consumers view their staff support and staff relationship to be critical to the sense of control that they feel in their lives. We would therefore recommend :

38. That the current wage and benefit structure for support service attendants be increased subject to a review process which includes an appraisal of the value of the attendant's role; and that budgets for SSLU and Outreach programs be expanded accordingly.

Third, if attendants are going to experience a strong sense of commitment to their work, then they need to feel a strong sense of responsibility and commitment to the people for whom they work. Right now, attendants may work with a number of clients, but their responsibility is to the organization that hired them.

This Review points to the fact that some consumers would like the option of either hiring their own attendant through an agency or through their own search. If consumers were to directly hire, train and supervise their own support staff, then they would no longer be clients, but rather employers, with their attendants directly responsible to them.

To view the consumer as an employer rather than a client represents a profound shift in our perceptions. Not only does this help to clarify the dilemma of who's in control, but it also creates a totally different context for the working relationship between an individual and the attendant. With the consumer directly involved in all aspects of the support, from the hiring to the supervising, there should be a greater opportunity for the development of mutual respect and commitment between the attendants and their employers (the consumers).

Obviously, if an individual is to assume the full responsibility of managing his or her attendant care, then funding should go directly to the individual. Therefore, based on the Review data and the above analysis, it is recommended:

39. That consumers who are interested in assuming direct responsibility for hiring, supervising and directing their own care (or who wish to hire their own administrative service to fulfill these functions), be provided with the necessary, individualized funds to meet their own specific needs.

Fourth, the discussion paper of the Ontario Advisory Council for Disabled People (1988) highlights the fact that "directing" one's own care is distinct from "managing" one's care. There are people who are fully capable of directing their own care who may not wish to undertake the responsibility of managing their own care. As we noted throughout this Review, people want options. A lot of personal energy and time is required to hire, train, and supervise an attendant, and some people may prefer to have this completely organized by an agency (such as with SSLU), or they may wish to have some of the initial advertising and screening handled by an agency, allowing them to make the final decision.

One Independent Living Centre follows a very careful process in helping people to find attendants. They begin by examining the possibilities within the person's support network - neighbours, friends, co-workers. As a second choice, the centre maintains a pool of attendants. The third option is to put an ad in the paper. The Centre has found that attendants stay longer if they have a one-to-one relationship.

A few of the organizations that were reviewed, as well as some of the independent living centres across the country, are developing individualized support mechanisms which link the consumer with individualized funding and supports. The concept is known as brokerage and will be discussed in depth in Chapter 10. It is important to introduce brokerage in this Chapter as a viable alternative for assisting people to manage their own support services.

Based on the above analysis, it is recommended:

40. That the Ministry of Community and Social Services, in consultation with consumers and service providers, explore and develop a range of options for assisting people who wish to be involved to some degree in the mangement of their own support.

Fifth, staff training is a highly contentious issue that will require careful policy consideration. While there is a strong push from some consumers and service providers to improve the calibre of staff through standardized college training for all attendants, there is an equally strong push to prevent certification and its potential professionalization. Consumers and some program directors argue that a college program will inevitably undermine consumer control in staff training. They claim that the person with the disability is the real "expert", not the college program or the attendant. If anyone is to receive training, it should be the consumer who may need some assistance in determining how best to teach his or her attendant.

Policy options have to be very sensitive to the conflicting viewpoints, and carefully assess the underlying issues. In this particular case, the issue is one of determining the appropriate methods of training staff so that the interests of people with disabilities are best served.

Based on the above analysis, it is recommended:

41. That the Ministry of Community and Social Services encourage community based training initiatives which are consumer controlled and directed, and which would be available to the full range of people involved in support care, including family members, neighbours, students, agency staff, program directors and consumers; and that consumer directed organizations such as independent living centres be

recognized as appropriate organizations to provide this training.

Chapter 10

COMPLETING THE FRAMEWORK: DIRECT FUNDING, BROKERAGE, AND LEGISLATION

The policy options and recommendations which have been identified so far in this Review emerge directly out of the data and analysis in each Chapter. There have also been themes in these Chapters, however, which as yet have not been developed into policy options or recommendations. These themes are larger than any one issue or concern addressed in this Review. These broader themes, to be explored in this Chapter, will contribute to building a coherent framework for responding to the support service needs of adults with physical disabilities.

The three major findings from our analysis of these themes are:

1. ***Several separate but interrelated sources of data point to the need to develop an option of direct funding to the individual consumer who needs independent living assistance.***

2. ***Several separate but interrelated sources of data point to the need for a support mechanism to assist people with physical disabilities to access and organize the services and resources they require to live independently in the community.***

3. ***There is recognition within many sectors that a more coherent legislative base must be established to support the philosophy and framework for delivery of support services.***

Each of these findings will now be discussed in light of our data.

DIRECT FUNDING TO THE INDIVIDUAL

In the last decade, there has been increasing interest in the development of more individualized funding to meet the support service needs of people with disabilities (De Jong, 1979; Lord, 1985; Salisbury, et. al., 1987; Pape & Church, 1987). Direct funding to the individual is the most unique and innovative form of individualized funding. As usually proposed, "direct funding" would go to the individual from government without going through an agency or third party. In Ontario, the idea of direct funding to the individual has been most clearly articulated as an independent living allowance (ILA). *An ILA can be described as a sum of money to a person for the purposes of meeting the person's independent living support needs.*

In the survey, people were asked directly if they agreed with the concept of an Independent Living Allowance. Seventy-eight percent of consumers said "yes", only 12 percent said "no", while 10 percent indicated they were "uncertain".

Confirming the survey results, in interviews people showed extensive interest in some sort of direct funding to the individual. A significant minority of consumers at every site mentioned it was time for a new funding approach. Several service providers and MCSS staff also noted the need for an independent living allowance.

> *"The ideal system would be some form of direct payment to consumers so they could purchase their own services." (Consumer Leader)*

> *"I would like to see a system that is portable, flexible and holistic. An Independent Living Allowance would give the greatest impact to needs such as personal growth and relationships." (Service Provider)*

> *"The Independent Living Allowance is ideal for those who want it...you would have more control over your life." (Outreach Consumer)*

Review Data Supporting Need for Independent Living Allowance

Throughout this Review, a number of themes have emerged from the data which support the need for an option of direct funding to the individual.

- Many consumers have a strong desire to have more control in the hiring, firing, and supervising of their support staff (Chapter 9). An ILA would give these consumers more control over their lives.

- Many consumers feel fragmented and frustrated in a system which has many agencies providing the services they need. Consumers want to have one attendant who carries out a number of personal support duties (Chapter 8). The ILA would enable consumers to contract with one person to fulfill all of their support service needs.

- SSLU projects, Outreach and other support programs only cover part of the province at the moment, resulting in regional disparities which are somewhat severe, particularly for disabled people living in isolated rural areas (Chapter 5). An ILA would enable these individuals to access funding for their supports without the need to set up a formal agency in that area.

- The evidence from consumers receiving an Order-in-Council is that individuals with severe and multiple disabilities can handle funds to contract for their independent living assistance. While the funds for Orders-in-Council must go through a third party agency, the consumers handle the funds directly. The ILA would be a concrete way to eliminate the Orders-in-Council, while responding to the needs of individuals with complex disabilities.

How Would an Independent Living Allowance Work?

Although the majority of consumers agree with the concept of an independent living allowance, not all consumers would want to manage their allowance.

In the survey, consumers were asked, "would you feel comfortable being responsible for administering the funds and managing your support staff?" Forty-five percent of people said "yes", forty-one percent said "no", while fourteen percent indicated they were "uncertain." For people who want the option to manage their support system, the individual living allowance is an attractive alternative. For people who do not want the financial management responsibility, other supports can be provided to the consumer through existing agencies or through a brokerage system to be discussed in the next section of this Chapter.

The most thorough and comprehensive work to date on how an Independent Living Allowance would work has been outlined in a series of papers by the Attendant Care Action Coalition (1986, 1987a, 1987b). The Coalition has proposed that the Independent Living Allowance cover the full cost of the assistance that the consumer needs to live independently. The essential feature of this approach is that:

> The consumer's own plan for meeting his/her needs should be funded including the costs to the consumer for managing and administering support services. Funding should be easily renewable, and easily be negotiated upon the presentation of a new plan (Attendant Care Action Coalition, 1987, b).

Consumers who choose this option would have responsibility for the delivery of the services and would handle functions such as payroll schedule, hiring, training, and firing of staff. It is important to make the distinction, as clarified by the Ontario Advisory Council for Disabled Persons (1988), that there is a difference between managing and directing your own care. As we have emphasized, all consumers would be expected to direct their own care to the fullest extent possible. While not everyone will choose to directly manage and be responsible for the financial administration of their assistance, consumers should be able to select their own administration system. Thus, the consumer who wants an agency to assist with service managment could choose such an option.

The Attendant Care Action Coalition (1986) points out that the Independent Living Allowance differs significantly from traditional services in the way that services are organized and delivered. The essential differences are worth noting. The independent living allowance:

- is oriented towards maximizing participation of the consumer, not treatment.

- is based on service goals which are defined by the service user, not the service provider.

- capitalizes on the consumers' strengths and needs by facilitating involvement in a range of environments, not just home and therapeutic environments, thus ensuring portability of the service.

- service costs are minimized by looking toward more generic services and resources, rather than using highly specialized mechanisms, and thus eliminating duplication in administrative structures.

In summary, the direct funding mechanism for service provision would put a subsidy into the hands of the consumer "so that s/he purchases the services directly and either manages and administrates the program him/her self, or purchases a managment service" (Attendant Care Action Coalition 1986, p. 10).

In order to better understand the strengths and constraints of an Independent Living Allowance, models from other jurisdictions were examined. Each of these will be briefly highlighted.

The California Approach. The California model of a personal assistance allowance has been operating for more than twenty years. Administrated by the 'In Home Services Support Program', consumers who require more than twenty hours of attendant care per week can receive an individual subsidy. The individual plan developed by the disabled person must be approved by a county social service worker based on a personal interview. While this service worker can call upon the expertise of an occupational therapist, the final number of attendant care hours agreed upon seems to be negotiable. The attendant care needs of the consumer are re-evaluated every six months or more often depending upon the nature of the disability (De Jong, 1979).

According to De Jong, the consumer is very much in the driver's seat in the California model. The consumer recruits, manages, and pays his or her own attendant. The limitation of the model is the potential control that the third party, the social service workers, has over the consumer. While more than 150,000 people are currently being funded in California programs, because it is available in only some counties of the State, many individual consumers cannot access this direct funding option.

Manitoba Self-Managed Care. It has been estimated that Manitoba has the most extensive services for people with physical disabilities in Canada (Applied Research Consulting House, 1984). Although their individualized attendant care is still somewhat limited, consumers and government officials in Manitoba have developed details of a self-managment care project. In conversation with consumer leaders from that province, it has been noted that a number of key principles have been established for the implementation of the project. It is proposed that the project would evolve through the Office of Continuing Care, which is similar to Home Care in Ontario. The individual would be entitled to receive directly, an equivalent sum of money 'in lieu' of the direct services which would be calculated to be needed by the individual and the Continuing Care Office. Payments would be made in advance and would include costs for administration and staff benefits. Like California, the Manitoba proposal involves the consumer or self-manager in taking responsibility for locating, hiring, directing, paying and if necessary firing whatever staff is required. The self-manager and Continuing Care would enter into an agreement, which would be reviewed every three to six months.

A key component in the Manitoba proposal is the support provided to self-managers or consumers. A number of these supports would likely be needed by disabled people who have little experience in management. These 'backup' services create a kind of brokerage system which will be discussed in the next part of this Chapter.

Cautions About an Independent Living Allowance

Some consumers and service providers express caution about the notions of direct funding to the individual through an independent living allowance. Many people were emphatic that, should this option materialize, it should only be one of the choices for consumers.

> *"Most people would like direct and individualized funding, but their choice should not be restrictive; they should increase Outreach options for people who do not want direct funding. You need to have a range of options, but based on choice." (Consumer Leader)*

> *"The independent living allowance is not appropriate for everyone. It is just one option. You might be able to manage your own care now, but not later." (Consumer: Community Meeting)*

Other people raised fears that they would have trouble managing an independent living allowance or that it would be too time consuming.

> *"It's a lot of work now to figure out all the programs and supports. I would need help." (Consumer: Outreach)*

Some fear was expres[illegible]hat with direct funding, money could be abused or wasted.

> *"Some people might do well, but others might simply blow their money; I see it as a step process; government should try the independent living allowance idea for some people and then evaluate it to see how effective it has been." (Service Provider)*

Most programs in the United States which provide a direct subsidy have built-in safeguards to minimize abuse of the system. Experience in Canada, with Orders-in-Council and Workers Compensation, suggest that people generally manage their money for support services extremely well. While some safeguards need to be carefully developed, there is the alternate danger that building in too many safeguards will defeat the purpose of a self-managed direct funding arrangement.

Issues in Delivery of ILA

There are two major delivery issues which would need to be resolved prior to the implementation of an independent living allowance.

Using Appropriate Government Funding Mechanisms. Under current funding arrangements between the federal government and the provinces, a large percentage of provincial funds spent on disability issues comes from Ottawa through the Canadian Assistance Plan (CAP). In 1984-1985, for example, more than 3.6 billion dollars was transferred to the provinces for 'provision of assistance and welfare services to and in respect of persons in need' (Statutes of Canada, 1967).

The reality of CAP funding in the disability area has been that the bulk of the money goes to maintain institutions and segregated services, although this was not intended in the original act. Two national organizations, the Coalition of Provincial Organizations of the Handicapped and the Canadian Association of Community Living, have both strongly urged the federal government to modify the CAP funding formula as part of a coherent strategy to support independent living and deinstitutionalization. What these groups envision are less programs which are block funded and more funding of individualized self-managed support services.

The Outreach program is currently cost shared under CAP, which is indicative of Ontario's interest in having the federal government participate in more individualized service. There seems little question that for Ontario to embark on a large individualized program such as ILA, the program will have to be eligible under the current cost sharing or as part of a revised CAP formula.

Accountability. Accountability is one of the critical issues which must be faced in the development and delivery of an independent living allowance. Can a system be designed which is primarily accountable to the consumer or are a number of other safeguards needed to ensure that public monies are spent appropriately? From an analysis of direct funding programs, it would appear that a minimum of safeguards should include:

- a method to verify the plan and the request of the consumer. This should be non-medical, and essentially be a review of the plan in terms of criteria which would obviously have to be developed.

- regular government audits of the spending of funds; as well as the use of periodic external evaluations of the program.

A major issue in the United States is whether or not direct funding to the individual should go through a third party, such as an agency. In interviews with the World Disability Institute, the main limitations to third party control seem to be the extra administrative expenses and the unnecessary controls on the consumer. On the other hand, it is suggested that utilizing appropriate agencies, such as independent living centres, can be a method of accountability and support for the consumer. These issues are discussed further in the next section on brokerage.

AN INDIVIDUALIZED SUPPORT MECHANISM - THE ROLE OF BROKERAGE

In the last few years, there has been growing interest in the concept that people with physical disabilities need individualized support mechanisms in order to access what they need in the community to live independently. When this support mechanism also links the consumer with individualized funding, and assists the individual in developing contracts with agencies in the community, this process is referred to as brokerage (MacLean & Marlett, 1987; McClugan & Salter, 1988; Salisbury et. al., 1987; Staiton, 1987). In Ontario, brokerage has not been widely experienced, but the idea of brokerage has been clearly articulated by the Attendant Care Action Coalition in a proposal which they entitled *Independent Living Assistance Brokerage* (1987).

Because of the importance of this emerging alternative, the strengths and limitations of brokerage were explored with consumers, service providers and key informants. In the survey, people were asked directly whether they agreed with the concept of brokerage. Brokerage was described as "a non-profit entity that provides a person called a broker to assist individuals with any one or all of the following: identifying needs, exploring community resources, contracting individual living supports, and monitoring the support services." Fifty-two percent of consumers said "yes" they agree with the concept of brokerage, 22 percent said "no", and 26 percent indicated they were "uncertain".

In interviews, consumer leaders and several service providers indicated strongly that some kind of a brokerage system should be put into place. A few consumers mentioned the idea and a small number of MCSS staff regionally and provincially also had thoughts about brokerage. Many of the comments about the need for brokers were discussed in the context of the independent living allowance.

> *"The independent broker will be needed to make individualized funding work. You need an ombudsman or broker who is separate from MCSS or the service providing SSLU and Outreach." (Consumer Leader)*

> *"It would be good to have a system...where consumers have direct control of the funds. The money may still need to go through an agency or broker. Many consumers will need support and will want an agency to do the hiring and monitoring." (MCSS)*

> *"The brokerage could be seen as a local agent with the sole purpose to co-ordinate delivery and attendant care services. It would not be responsible for providing funding and it would not be deemed the employer...the functions would be to co-ordinate funding and to contract service delivery between the Ministry and social services and the disabled person..." (Consumer Leader)*

Review Data Supporting Need for Brokerage System

Throughout this Review, a number of themes have emerged from our data which support the need to consider the role of brokerage in the development of a comprehensive support system for people with physical disabilities.

- Many consumers have a strong desire to have more control in the hiring, firing, and supervising of their support staff (Chapter 9). Because people want to manage their supports to the greatest degree possible, there will need to be a support mechanism that is available with an independent living allowance. The self-directed care proposal in Manitoba outlines in great detail the kind of education and support that consumers will need for a self-managed system. Brokerage would provide some of this support.

- Many consumers feel fragmented and frustrated in a system which has many agencies providing the services they need. Agencies currently have very little direct accountability to the consumer. Brokerage would create a more consumer driven system, with brokers helping individuals develop plans for the services they need by contracting with agencies and linking resources in as co-ordinated a fashion as possible.

- There are people who believe that a direct funding approach will not work without a brokerage system, and that brokerage creates the "process" for individualized funding and service.

- People who are having difficulty directing their own care may need advocates to safeguard involvement in the attendant care process (Chapter 7). The broker would have an important role to play in helping individuals find advocates and identify other people in each person's network who can be supportive.

How Would Brokerage Work?

In order to gain a greater sense of what people thought might be a realistic role for brokerage, consumers were asked in the survey whether they thought a broker could assist them in meeting more of their basic needs. Thirty-eight percent of consumers said "yes"; 39 percent said "no", and 23 percent were uncertain. It is not clear, of course, whether consumers said no because they feel they could manage their own independent living allowance without support or whether a number of people said no because they prefer their current service arrangement. Nevertheless, it is interesting that more than one-third of the people surveyed said that they could benefit from a broker. In addition, people identified the roles they felt a broker could play in their lives. These are outlined in Table 14.

Although these data do not tell us exactly how a brokerage system would function, consumer perceptions point to some of the key roles a brokerage system might play. In Ontario, the Attendant Care Action Coalition (1986, 1987a, 1987b) has proposed an independent living assistance brokerage which they define as a non-profit corporation, whose main function would be to provide a "process".

Table 14

Consumer Perceptions of Roles Broker Can Play

Area	(%)
helping to identify my needs	76
planning with me to figure out goals and directions	67
exploring community resources I need	70
contracting with attendants and monitoring my supports	63
others	65

> It is a service which provides assistance to an individual to exercise determination through the effective articulation of needs and abilities. The service can assist in some cases in negotiating for the appropriate funding and/or services through the entire range of home and community supports.

> The Brokerage builds into this process a mechanism for individuals to play the major decision-making role in determining the needs they require.
>
> The staff person or agent delivering the service is called a "broker". The broker provides technical advice to the disabled individual who is the primary focus of all planning and supports. In order to do this effectively and to avoid a purely administrative or 'control' system from emerging, the broker needs to function as a partner with the individual. An individual can be referred by a variety of sources including self, family, or agency staff. The brokerage will strive to ensure unimpeded access to Brokerage services. At any time of the process the individual may choose to proceed on his/her own (Attendant Care Action Coalition, 1987b, p. 5).

The proposal from the Coalition emphasizes 6 ways that the broker functions with the consumer:

- initial contact
- network identification, assisting the individual, and exploring and developing a personal network
- general service planning, including the individual's desired role and the community and supports required to fill this role
- community resource exploration, including the gathering of data so that the consumer can make an informed choice
- contract negotiation, including the funding required to purchase the required service and explaining the nature of this service
- monitoring and follow-up to ensure that the individuals' needs are being met.

In order to better understand the strengths and dilemmas of a brokerage system, we examined models of other jurisdictions. Two of these will be briefly highlighted.

Community Living Society. The Community Living Society in Vancouver was the first group to develop one type of brokerage in Canada.

It was initiated by a parent group which was trying to devise innovative ways to support their sons and daughters who were coming home from institutions. The brokers, staff members with the Society, develop general service plans with the person, the family, and the referring agency. The broker, once funds are allocated from the government, matches the person's need to the services available in the community.

This kind of agency brokerage makes the agency itself directly accountable for the expenditures and the services provided to the consumer. In the case of the Community Living Society in Vancouver, many of the services that were made available were developed by the Society itself. Although there is much to learn about the process from groups like the CLS, this model of brokerage has numerous limitations. For one thing, the agency is still in control of the dollars for the person. In addition, brokers have a potential for a real conflict of interest because the agency for which they are working is also the agency which is providing the direct service. It is unlikely that this agency model of brokerage could apply to attendant care, where individualized service and consumer control is paramount. It appears that there need to be other ways of safeguarding the individualized funding process, other than by creating a brokerage system dominated by agencies.

Calgary Association for Independent Living. The service brokerage model developed by the Calgary Association for Independent Living (CAIL) reflects an independent brokerage approach. Although the Alberta government has not made funds available specifically for brokerage, CAIL has been successful in accessing specialized government funding designated for severely handicapped individuals. The role of the broker is to help the individual identify his/her needs and service requirements and then to select, with the consumer, a support person or agency from CAIL's service registry. The broker also assists the individual in drawing up the contract, and helps the consumer and the service provider to establish an appropriate payment procedure.

In a national study on independent living centres (Lord & Osborne-Way, 1987), consumers of brokerage within CAIL indicated they were very pleased with the assistance they had received. In general, consumers appreciated the individualized supportive nature of the process. The unique feature of this kind of brokerage is that it is carefully linked with the development of building personal support networks. While the broker can play such a role during the development of the individual plan, in Calgary a second staff person is available to co-ordinate support networks with consumers.

The Calgary Association for Independent Living believes that having brokerage within an independent living centre helps create a place or "fixed point" for the consumer to bring concerns and questions. Such centres can also provide attendant registries and resources for consumers, addressing a wide range of needs, including the consumers' need for have for support and education in directing and managing their own care.

While this type of independent brokerage is very similar to what is being proposed by the Attendant Care Action Coalition, the placement of the brokerage system within an independent living centre is an intriguing notion. The Ontario Advisory Council for Disabled Persons (1988), has recommended that the government of Ontario encourage the development of independent living centres in urban and rural areas of the province. There is no question that most independent living centres could provide an important focal point for brokerage and individualized funding for the province. This is particularly true for those centres which do not provide a lot of other direct services.

Key Delivery Issues for Brokerage

In the development of any brokerage system there are three main issues which will need to be addressed.

The degree to which brokerage must be independent. Some people who were interviewed indicate that the independence of the broker from the service system is vital. It seems clear that the broker who pays allegiance to a service provider will not always be able to work on behalf of the consumer. An independent brokerage would need to be located in a setting which is free of conflict of interest with the service sector. This "fixed point" of response has been noted as a key dimension in creating a responsive individualized system (Lord, 1985; McClugan & Salter, 1988).

How to structure a brokerage/individualized funding system which is responsive to the consumer. The fear expressed by two or three people is that a poorly designed brokerage system could lead to more beauracracy in the service system. An effective brokerage system should do just the opposite - it streamlines consumers' concerns and assists the consumer in accessing what they need. Some recent authors have maintained that the training of brokers is a critical dimension in safeguarding the system (Salisbury et. al.,1987; Staiton, 1987). The broker must work for the consumer, and the brokerage agency itself must be directed by consumers.

The other element which keeps a brokerage system responsive to the consumer is the availability of direct individualized funding. It is the funding which enables the broker to make contracts with the consumer and service providers, and to tailor services to the needs of the individual. This is also the most fundamental way by which brokerage differs from case managment. Case managers do some of the same things as a broker, but they have no control over funds and usually they have an agency base.

How to maintain a brokerage system so that it is a mediating structure between the individual, the community and the service system. Although brokerage itself can be a fairly technical process, the goal is to create "mediating structures" or bridges between the individual, the community, and the services. This is probably best accomplished by brokerage services which include a focus on the consumer's network of support (Salisbury et. al. 1987). The social network in many ways is the consumer's best safeguard for personal empowerment and security. It has been noted that people with physical disabilities often have limited relationships and social networks. In addition to its funding and contract functions, a brokerage system would seem to be quite limited unless it also focuses on people's need for social networks and community integration.

NEED FOR COHERENT LEGISLATION

There is a recognition within many sectors that there is the need for coherent legislation to support the framework that has emerged in this Review for responding to the support service needs of people with physical disabilities. The main concerns people express include:

- there are too many different acts being used to provide services.
- the Homes for Retarded Persons Act is totally inappropriate as a piece of legislation, particularly for use with people with physical disabilities.
- the Ministry Act is too general in nature, and more detailed enabling legislation is required.

A debate heard during this Review revolves around whether or not a specific new piece of legislation should be developed to address the unique needs of people with physical disabilities. There are arguments in favour of specific legislation:

- attendant care and independent living assistance needs could be addressed for people with physical disabilities.

- a personalized and direct funding mechansim could be provided, similar to the model legislation proposed by the World Disability Institute.

On the other hand, there are arguments against such specific legislation. People taking this position tend to support the idea of developing "generic" legislation which could be used to service several populations. It seems that such legislation would be warranted if:

- it provided for an individualized, direct funding mechanism.

- it could be used to address support services of not only physically disabled persons, but also of other groups such as people with brain injuries, elderly people, and individuals with developmental handicaps.

- it could be used to create individualized support services which are available, accessible, and flexible.

MCSS is currently examining the potential of "generic" community services legislation, which will need to take into account legislative issues raised in this Review.

SUMMARY AND RECOMMENDATIONS

Several themes and issues identified throughout this Review have pointed to the need for a framework and philosophy to guide support services for citizens with physical disabilities. Several recommendations have pointed toward the development of this framework. This Chapter completes the framework with the development of the option of direct funding to the individual, a support mechanism called brokerage, and a coherent legislative base.

The framework carefully weaves together direct individualized funding with a fixed point of response for the consumer. In other words, the consumer has a place to go where he or she can depend upon people for support. There is a technical, supportive service in the form of a broker who can assist with a variety of functions which the consumer needs, including the contractual arrangements for funding the appropriate support service. The broker has a variety of roles which have been discussed in some detail.

Both of these alternatives, direct individualized funding and brokerage, would be new initiatives in the physical disabilities field. It is significant to note that several groups in Ontario and elsewhere have strongly supported the idea of direct funding and systematic support mechanisms for the consumer. These groups include:

- Attendant Care Action Coalition
- Ontario Advisory Council for the Disabled
- Coalition of Provincial Organizations of the Handicapped
- World Disability Council

It is important to reiterate that the goal of policy options in the physical disabilities area must focus both on reform of the system and on ways of improving access to resources and quality services for the consumer. While direct individualized funding and brokerage are designed to improve access and distribution of resources, system reform must also be addressed through the other recommendations in this Review. An individualized brokerage system will also assist in system reform by producing positive consumer outcomes, such as better educated consumers, more consumers who are empowered and aware of their rights and obligations, and more consumers with the resources to manage and direct their own supports.

In light of our analysis in this Chaper and throughout the Review, it is recommended:

42. That an independent living allowance be adopted as a direct funding option to individuals with physical disabilities who require independent living assistance or attendant care; and that guidelines to be developed for the allowance include simple and flexible mechanisms for access and accountability.

43. That four pilot brokerage projects be established in Ontario; that existing independent living centres or equivalent groups that do not provide direct services sponsor the brokerage projects; that a committee of consumers and MCSS staff be utilized to set up, monitor, and evaluate the pilot projects; and that the committee determine how the projects will be expanded.

44. That MCSS carefully consider the findings from this Review in its consideration of new community services legislation.

Chapter 11

FOLLOW-UP: PHASE II OF THE REVIEW PROCESS

When MCSS announced this Review in the fall of 1987, Ministry officials indicated at that time that there would be a phase II of the Review process in order to consolidate the findings and embark on a consultation and implementation process.

It is proposed, by the research team and the Advisory Committee, that this Review report be used as the basis of phase II initiatives.

The recommendations made throughout this report fall into several major areas which can be used for phase II and the development and implementation of a long range plan.

The recommendations suggest that initiatives are needed in the following four areas:

1. Principles and philosophies to guide policy and program decisions.
2. Strategic planning to assess proposed policy changes, to implement program recommendations, and to establish a long range plan.
3. Clear guidelines to assist in program implementation.
4. Research and/or demonstration projects in areas that need to be better understood.

In Table 15, there is a list of all the recommendations made in the report, divided into these four sections. While not all the recommendations fit easily into one particular section, this will provide a general framework for thinking about the planning, activity, and resources which will be required for phase II.

To foster public participation, as emphasized by MCSS in its Corporate Plan, it is proposed that task forces be set up to assist with phase II. Task forces could be utilized to;

- React to the Review Report.
- Participate in strategic planning sessions.
- Assist in finalizing details for program guidelines.
- Assist in the development and implementation of research and demonstration projects.

It is expected that the current Review Advisory Committee would either become an integral part of these task forces or would continue to be involved in an overall advisory capacity. Whichever option is chosen, task forces should include consumers and other interested parties, including representatives of groups such as the Ontario Advisory Council for Disabled Persons, Attendant Care Action Coalition, Canadian Paraplegic Association, and Persons United for Self Help in Ontario.

One desired outcome of phase II is clear -- a well developed long range plan and new funding approach which reflects the learnings of this Review, and which would have support among government, consumers, and voluntary organizations. Other outcomes must have more immediate impact on citizens with physical disabilities. This Review has demonstrated there are many unmet support service needs which must be addressed as soon as possible.

Table 15

Areas Where Major Initiatives Needed

1. Principles and Philosophies to Guide Policy and Program Decisions

1. That the Ministry develop a philosophy and framework to guide its support services in Ontario that acknowledges that the core needs of physically disabled people are the same as the core needs of non-disabled citizens; and that this philosophy be used as the basis for

designing support services which are community-based and non-medical in their approach.

2. That the philosophy and framework guiding support services in Ontario recognize that each person's core needs be met in different ways; and that supports for independent living be provided in an individual and flexible way, reflecting this cornerstone principle.

3. That attendant care services be designed with the goal of relieving family and friends of the major responsibility for providing support services, thereby reducing disabled persons' dependence on their family and friends.

32. That individual consumers be given the choice of deciding which, if any, agencies they want to involve in providing their support; if they so choose, consumers should have the option of selecting individual funding and arranging for their own support, with or without the involvement of an agency.

37. That providers of support services formally acknowledge that their primary goal is to respect the right of the individual to direct his or her own care and to provide support to individuals who require assistance in learning how to direct their own support.

2. Strategic planning to assess proposed policy changes, to implement program recommendations, and to establish a comprehensive long range plan

Family Support

4. That individualized support services be recognized as playing a critical role in reducing individual and family stress, and that budgetary allocations to these programs reflect their key function in prevention.

5. That the Ministry recognize that the current support programs have limited impact because they respond to only a portion of individual needs; and that to move beyond this initial level of impact, a more comprehensive plan capable of responding to the broader needs of individuals be developed.

Long Range Plan

6. That a comprehensive plan for responding to the broader needs of individuals include both an individual planning mechanism and the option of individualized funding.

7. That the Ministry of Community and Social Services significantly increase the amount of support services and expand its programs for attendant care and independent living assistance for people with physical disabilities not yet receiving any service, and

8. That the Ministry phase in new monies for individualized support services as part of a long range comprehensive plan to address the needs of people with physical disabilities in Ontario.

10. That the Ministry of Community and Social Services cooperate with the Ministry of Health in developing a plan to move people identified in a study out of chronic care institutions and nursing homes over the next five years; and that the plan include a commitment to "zero entrance" of inappropriately placed physically disabled adults into such facilities.

36. That the comprehensive long range Plan include the concept of a lead agency as a way of providing greater co-ordination at the individual level.

42. That an independent living allowance be adopted as a direct funding option to individuals with physical disabilities who require independent living assistance or attendant care; and that guidelines to be developed for the allowance include simple and flexible mechanisms for access and accountability.

43. That four pilot brokerage projects be established in Ontario; that existing independent living centres or equivalent groups that do not provide direct services sponsor the brokerage projects; that a committee of consumers and MCSS staff be utilized to set up, monitor, and evaluate the pilot projects; and that the committee determine how the projects will be expanded.

Outreach Options

12. That consumers be given the option of either obtaining service from Outreach or receiving individual funding directly from the Ministry to purchase and manage their own service.

13. That the Ministry seek more support from the Ministry of Housing to expand the number of accessible, affordable housing units in the province and to ensure that municipalities enforce building code standards.

Youth

22. That the Ministry of Community and Social Services, in collaboration with the Ministries of Education, Labour, and Skills Development develop a comprehensive initiative which will impact upon the transitional issues affecting youth (16-21) with physical disabilities.

Co-ordination

34. That for those people who wish to continue receiving their support from multiple agencies, that the current approach be maintained as an alternative; for example, some individuals would like to maintain the option of having someone with a medical background perform specific personal care functions such as injections or catheterization.

35. That the Ministry of Community and Social Services initiate discussions with other Ministries, particularly Health, to attempt to increase their understanding of the serious negative impact on the lives of consumers who must receive services in a system that lacks co-ordination; and that the Ministry examine in detail ways to implement a policy option to maximize individual service co-ordination.

Consumer Control

39. That consumers who are interested in assuming direct responsibility for hiring, supervising and directing their own care (or who wish to hire their own administrative service to fulfill these functions), be provided with the necessary, individualized funds to meet their own specific needs.

40. That the Ministry of Community and Social Services, in consultation with consumers and service providers, explore and develop a range of options for assisting people who wish to be involved to some degree in the mangement of their own support.

41. That the Ministry of Community and Social Services encourage community based training initiatives which are consumer controlled and directed, and which would be available to the full range of people involved in support care, including family members, neighbours, students, agency staff, program directors and consumers; and that consumer directed organizations such as independent living centres be recognized as appropriate organizations to provide this training.

3. Clear Guidelines to Assist in Project Implementation

14. That all future SSLU projects be developed on principles of community integration, to ensure that the project location, size, housing type, and function of the support services be designed to maximize independent living and community participation.

15. That future support service policy be tied to the individual rather than to housing models; and that an array of individualized support services that are not based upon a continuum, be developed to maximize consumer choice.

16. That current and future SSLU projects be encouraged to develop innovative approaches to support services which would include clustering of people in neighbourhoods, not just in a single building.

17. That the Ministry promote individualized transitional services for people in their permanent community homes; that the Ministry commission a study to design the most effective way to develop and deliver such individualized transitional services; and that the study examine the role of independent living centres as a vehicle for providing these services.

Program Coherence

18. That the Ministry develop clear guidelines to assist MCSS Area Offices in determining which organizations are most appropriate to provide

future Outreach and SSLU programs in a manner that fulfills the goals of independent living and consumer participation.

20. That the Ministry develop a resource team whose mandate would be to assist agencies in developing their capacity to deliver coherent, consumer oriented services, while respecting local decision making and initiatives.

Consumer Participation

19. That a high degree of consumer participation be mandated for new SSLU and Outreach agencies; and that current projects be required to phase-in plans of how they will increase consumer participation in their agency structure over the next two years.

Youth

21. That youth with physical disabilities who are receiving Special Needs at Home funding be transferred to the Outreach program when they turn 18 if they require attendant care.

Directing Own Care

23. That a broad definition of "directing your own care" be developed to include a component of support for those who need it; and that this new definition be adopted by the Ministry as a training tool for both individuals and attendants in learning how to "direct one's own care".

24. That a method to support those consumers who need assistance in directing their own care be developed; that independent personal advocates be used to ensure that rights are being safeguarded; and that independent groups, such as independent living centres, be utilized as sources of support and advocates.

Restrictive Guidelines

25. That the requirement that the consumer have a back-up "be eliminated" as a criterion from the Outreach program; and that individuals who lack a back-up system be given assistance to develop a support network as part of their independent living service.

26. That any SSLU policies, either at the Ministry level or in local interpretation, which force families to be split up in order to access service, be immediately eliminated; that any future SSLU projects include plans for family units; and that in the interim period, such consumers be eligible for Outreach services to enable their families to stay together.

28. That the Outreach criterion restricting relatives from being hired as attendants be eliminated; and that Outreach programs be encouraged to provide options for consumers, ranging from the use of full-time agency staff to part-time neighbours or friends as attendant care workers.

29. That the 3-hour restriction in Outreach be eliminated and that a more flexible system of assessing needs and providing support service be implemented on an individual basis.

30. That there be no minimum time requirements, but that individual funding be encouraged as a way of enabling people with erratic or very low scheduling needs to be accommodated.

Attendants' Role

27. That attendant care be available in settings outside the home in which the consumer requires personal support such as at work, at school, while on outings into the community, or on trips (either pleasure or business); and that the Ministry phase in such a policy initiative on a demonstration basis.

33. That the role of the Outreach attendant care worker be expanded to include not only personal care, but also homemaking and routines such as taking medication and/or needles, catheterization, and bowel and bladder; and that these latter routines be clearly defined as personal care and included in the role of attendant care workers for consumers who so choose.

38. That the current wage and benefit structure for support service attendants be increased subject to a review process which includes an appraisal of the value of the attendant's role; and that budgets for SSLU and Outreach programs be expanded accordingly.

4. Research and/or demonstration projects in areas that need to be better understood

9. That the government commission a study to be done with physically disabled people in institutions, chronic care facilities, and nursing homes to determine the exact number of people who are in need of having the opportunity to move to the community; and that this study include an analysis of the support which would be required, and the framework for the deinstitutionalization plan.

11. That the catchment areas of existing Outreach programs be enlarged, and/or new programs be added, to ensure that individuals have the choice to access the nearest Outreach program.

31. That a pilot project be initiated in order to learn how people with very high physical care needs, such as respirator-dependent quadraplegics, can live independently with attendant care support.

42. That an independent living allowance be adopted as a direct funding option to individuals with physical disabilities who require independent living assistance or attendant care; and that guidelines to be developed for the allowance include simple and flexible mechanisms for access and accountability.

43. That four pilot brokerage projects be established in Ontario; that existing independent living centres or equivalent groups that do not provide direct services sponsor the brokerage projects; that a committee of consumers and MCSS staff be utilized to set up, monitor, and evaluate the pilot projects; and that the committee determine how the projects will be expanded.

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Appendix A

Summary of People Interviewed and Surveyed, and Summary of Attendance at Community Meetings.

People interviewed:	
Consumer Leaders	29
Outreach Consumers	32
Outreach Waiting List	18
SSLU Consumers	51
MCSS Program Supervisors	7
MCSS Key Informants	6
Service Providers	
Outreach	12
SSLU	12
Orders-In-Council	4
Waiting Lost OIC	4

People Surveyed:	
Consumers sent 176 responses-received	111(63%)
Attendants sent 174 responses-received	77 (44.3%)

People who attended Community Meetings	
Barrie	35
Hamilton	15
Kingston	40
London	39
Ottawa	38
Sudbury	36
Thunder Bay	4
Toronto 1	85
Toronto 2	71
Total	363

Appendix B

Areas Where Consumers Would Like More Independence and Control

Area	Importance of Having More Control			
	OK As Is	Less Important	Important & Very Important	Total
	%	%	%	N
1.Daily routines/rhythms	33	3	64	100
2. What I eat	37.6	5	57.4	101
3. How much money I have	18.8	4	77.3	101
4. Who my friends are	30	4	66	100
5. Seeing my friends	28.6	2	69.4	98
6. Having a job	22.9	16.7	60.4	96
7. Time to myself	38	11	51	100
8. Feeling and being safe	24.2	3	72.7	99
9. Who assists me	23	5	72	100
10.Where I live	28	2	70	100
11.Who I live with	34	4.1	61.8	97
12.What I do for my leisure	32	8	60	100
13.My means of transport	17	2	81	100
14. Assistive devices	24.2	7.1	68.7	99
15. Involvement with family	28.3	9.1	62.6	99

16. Using community resources	21	15	64	100
17. School/learning opport.	23.7	29.9	46.4	97
18. Contributing to the community	36.7	20.4	42.5	98